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An exploration of the factors that influence nutritional recovery following critical illness: A mixed methods study

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Declaration

I here in declare that this thesis has been composed by me and that the research on which it reports is my own work.

Judith Merriweather

June 2013

"Every careful observer of the sick will agree in this, that thousands of patients are annually starved in the midst of plenty"

Florence Nightingale (1859)

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Abstract

Survivors of critical illness suffer from a range of problems affecting physical, psychological and social well-being (Needham et al 2011). Weakness, fatigue and malnutrition are highly prevalent during the months following a critical illness. Few studies have systematically and comprehensively explored the factors that influence nutritional recovery or ways to overcome them. The aim of this study was to provide a comprehensive understanding of the factors influencing nutritional recovery, and the relationship between them, in post intensive care (ICU) patients. A model of care was then developed to improve current management of nutrition for patients recovering from critical illness.

Grounded theory methodology was used with a mixed method research design. Nutritional status and intake were assessed on discharge from ICU and at three months post ICU discharge. The process of nutritional recovery during the first three months post ICU discharge was explored from a patient perspective and at the level of ward organisation of care, through observation of practice and interviewing patients and staff.

Seventeen patients, who had required greater than 48 hours ventilation, were recruited on discharge from the ICU. On transfer to the ward 9 of the 17 patients were assessed as well-nourished and 8 were malnourished using Subjective Global Assessment. At three months post ICU discharge 14 patients were followed up (1 lost to follow up, 1 incapacitated following illness and 1 went overseas). Seven of these were classified as well-nourished and the other 7 were malnourished. Patients universally failed to meet their nutritional targets during their ward stay and although intakes had improved by three months post ICU discharge, the majority of patients were still not achieving their nutritional requirements.

Qualitative data revealed that patients' nutritional intake was influenced by interrelated system breakdowns during the recovery process; this emerged as the overarching core theme. Three sub-themes were ‘experiencing a dysfunctional

body', 'experiencing socio-cultural changes in relation to eating and 'encountering organisational nutritional care delivery failures'. This study identified connections and interrelations between these concepts and provided new insights into the factors that influence the nutritional care of post ICU patients.

In order to optimise nutritional rehabilitation in this patient group a model of care has been developed which addresses the identified organisational and patient related factors that were shown to influence the nutritional recovery of patients after critical illness. This nutritional strategy will need to be evaluated in clinical trials or quality improvement programmes.

Contents

Chapter 1: Introduction

1.1 Overview of chapter

This chapter describes the background to this doctoral thesis. Firstly it details the current research highlighting the complexity of problems faced by patients after critical illness and the need for rehabilitation in this patient group. The rationale for the current study is then explained incorporating the researcher's personal and professional interests and her background work which has focused on identifying the nutritional problems faced by post intensive care unit (ICU) patients. Finally the purpose of the doctoral study and the structure of the thesis are described.

The researcher wants to highlight that the terms 'intensive care' and 'critical care' are used interchangeably and this is because they hold the same meaning; "*areas in a hospital where patients at high risk of developing, or already suffering from, multiple organ dysfunction are managed and cared for*" (ICNARC 2009).

1.2 Background

1.2.1 Current research evidence

The advent of intensive care units (ICU) has improved the survival of patients with complex multiple organ system failure. However, "*many (intensivists) considered intensive care as a 'service stop-over' with little concern for where the patients came from or where they were going*" (Griffiths & Jones 2002 p1). The very nature of the critical illness leads to ensuing problems that need to be addressed during recovery (Griffiths and Jones 2007).

Increasing awareness of a prolonged and suboptimal recovery for ICU patients led to the King's Fund Panel (1989) commissioning work to explore the costs, morbidity and mortality outcomes from ICU. Since then a plethora of work has demonstrated that ICU survivors and their carers cope with severe disability during a protracted and often incomplete recovery (Herridge 2011). The disability suffered includes physical, emotional, psychological, and social problems, which are prevalent and often severe (Desai 2011, Needham 2012). Health related quality of life (HRQoL) is reduced and recovers slowly (Oeyen 2010).

A report (DH 2005) and a NICE guideline (NICE 2009) highlighted the need to improve rehabilitation for this patient group. The systematic review undertaken during NICE guideline development indicated a lack of high quality research concerning interventions to improve rehabilitation of these patients. The following issues in this area have been identified:

1.2.1.1 ICU patients utilise enormous hospital resource

Of the 10,000 patients admitted annually to 25 ICUs across Scotland 20% die in the ICU and up to 40% within 12 months of discharge from ICU (Wright et al 2003, SICSAG 2007). National audit data show that, in Scotland, patients spend a mean of 5 days in intensive care, utilising about 50,000 ICU bed days annually, at an estimated cost of £75 million (SICSAG 2007). Numbers of patients are projected to increase as a result of the ageing population, greater complexity of treatments, higher expectations of health care, and improving ICU survival rates. Patients with a length of stay ≥2 days comprise 30-40% of all admissions, but utilise 60-80% of ICU bed days. Length of ICU stay has a skewed distribution as the median length of stay for ICU is 2 days, the mean is 5 days. This group also use disproportionate hospital resource post-ICU discharge, and across Scotland around 20,000 acute bed days are utilised annually by such patients after ICU discharge (SICSAG 2007). Importantly, survival from critical illness is improving year on year, as evidenced by an ongoing reduction in standardised mortality ratios. This has resulted in progressively more patients discharged from hospital following a critical illness (SICSAG 2012).

1.2.1.2 Wide ranging health problems after ICU stay

Outcome from critical illness is generally measured using short-term mortality (typically 20-25% in ICU; 30-35% in hospital), or ICU-based measures such as days on a ventilator and rates of hospital-acquired infection. However, increasing attention is being paid to the longer-term impact of critical illness on patients' health and also on families and carers. The long term effects include a range of problems affecting physical, psychological, and social well-being. Accordingly, there is a high prevalence of patients reporting a low Health Related Quality of Life for many months after ICU discharge (Oeyen 2010).

1.2.1.2.1 Psychosocial issues

The health problems that follow critical illness have been termed the "post-ICU syndrome" (Herridge 2007, Needham et al 2011). Problems with psychological health and social functioning are common (Cuthbertson et al 2004, Rattray et al 2005). Anxiety, depression, and post-traumatic stress reactions are reported in 10-40% of patients at 3-6 months (Jones et al 2000, Cuthbertson et al 2004, Hopkins et al 2004, Rattray et al 2004). Emotional problems have been associated with a range of factors during hospital stay including younger age, female gender, ICU length of stay, delirium, excessive sedation, "unreal experiences", nightmares and hallucinations (Rattray et al 2005).

1.2.1.2.2 Physiological issues

Physical impairment is typified by malnutrition and patients can lose 10-30% of their body mass during critical illness (Griffiths and Jones 1999). Recovery is further delayed by joint stiffness, pain, fatigue and breathlessness. Muscle weakness is particularly prevalent occurring in 25-50% of critically ill patients (Stevens et al 2007) and strongly associated with poor outcome (Herridge 2007). Functional impairment results in disability and studies have shown high levels of disability in post ICU patients (Barnato et al 2011). The International Classification of Functioning, Disability and Health (ICF) highlights that functional disability affects bodily function, structure and activity (WHO 2001). The ICF also recognises the social aspects of disability (WHO 2001). There is a paucity of studies that examine this aspect of disability in patients after critical illness as current research has focused on a very medical model to study disability in this patient group.

1.2.1.3 Lack of coordinated rehabilitation following ICU discharge

Despite the wide range of psychosocial and physiological problems faced by patients after critical illness, rehabilitation strategies post ICU discharge are inconsistent and disjointed. The most comprehensive guidance about rehabilitation comes from the National Institute of Clinical Excellence (NICE) who commissioned a short clinical guideline for Rehabilitation following critical illness (NICE 2009). This report identified the paucity of high quality evidence to guide rehabilitation and highlights the current piecemeal approach to rehabilitation following ICU discharge.

1.2.2 Current rehabilitation strategies for patients after critical illness

There is remarkably little dietetic specific research during rehabilitation and the NICE (2009) guideline failed to identify any studies that specifically addressed nutritional rehabilitation in patients after critical illness. Reflecting this, nutrition issues receive relatively little attention in the NICE guideline. Reference is made to nutrition at the point of discharge from critical care when the NICE guidance states that healthcare professionals should *'ensure that the transfer of patients and the formal structured handover of their care are in line with "Acutely ill patients in hospital" (NICE clinical guideline 50). This should include the formal handover of the individualised, structured rehabilitation programme*' (NICE 2009 p10). The NICE clinical guideline 50 states that: *'the formal structured handover of care should include:*

- *a plan for ongoing treatment, including drugs and therapies, nutrition plan, infection status and any agreed limitations of treatment*' (NICE 2007 p14).

No specific recommendations for nutritional rehabilitation are made in the NICE guidance for ward based care however it is recommended to '*give patients the following information before their discharge to home or community care.*

- *If applicable, information about diet and any other continuing treatments'* (NICE 2009 p13).

It is interesting to note that many of the NICE guideline recommendations are based on the expert opinions of the guideline development group; a dietitian was not included as part of this group. Although the recommendations included a 'nutrition plan' and 'information about diet,' there is no available evidence to provide any detail in relation to the content of the recommended plan and information. The guideline development group also acknowledged the need to undertake studies to investigate the optimum timing of interventions, and their clinical and cost effectiveness.

Current rehabilitation strategies have focused on different stages of the patient's journey. These stages have been identified as during the critical care stay, during ward based care and after discharge from hospital (NICE 2009, Walsh et al 2012). The strategies, with particular reference to nutritional rehabilitation strategies, are discussed below under each of the identified stages.

1.2.2.1 During the critical care stay

There are no studies that have looked at nutritional rehabilitation in the ICU and the focus of rehabilitation strategies during this stage of the patient's journey has been on physical therapy. A recent systematic review and meta-analysis of trials of physical therapy in ICU was carried out by Kayambu et al (2013). The review found that physical therapy in ICU had beneficial effects on quality of life, physical function, muscle strength, duration of ventilation, ICU stay and hospital stay. However, few of the studies reviewed by Kayambu described the intervention delivered making it difficult to translate the effects into clinical practice. Conversely, it is difficult to ascertain if any negative result occurred as a result of an ineffective intervention or because it was not delivered as intended.

None of the 10 randomised controlled trials included in the review made any reference to nutritional recovery. Kayambu et al (2013) focused only on exercise rehabilitation however rehabilitation includes other factors such as nutrition, speech and language therapy, occupational therapy and psychological interventions (Salisbury & Walsh 2013).

1.2.2.2 During ward based care

The NICE (2009) guideline identified one randomised controlled trial that evaluated the effectiveness of a 6 week self-help rehabilitation manual (Jones et al 2003). In this study 126 patients were either randomised into a control group who received ward visits, three telephone calls at home, and clinic appointments at 8 weeks and 6 months or an intervention group who received the same plus a 6 week self-help rehabilitation manual. The manual contained information on physical and psychological problems and incorporated a self-directed exercise program. Nutritional information was basic advising small frequent meals, snacks or milky drinks between meals and eating slowly. The results showed that intervention patients had improved physical function scores at the 8 week and 6 month follow up clinic visits. This study supports the hypothesis that targeted approaches could improve physical function and reduce disability during the months immediately following ICU discharge. No nutrition related outcomes were measured in the study nor was any mention made as to whether the patients adhered to the nutritional advice provided. Despite the inclusion of the nutritional information in the manual, little is understood about the clinical effectiveness of nutritional interventions.

1.2.2.3 After discharge from hospital

The majority of rehabilitation research after critical illness has targeted interventions after discharge from hospital. Moran et al (2005) investigated a nurse led telephone follow up service that was established to offer the opportunity for patients to discuss issues related to their ICU stay and any ongoing problems. Patients were contacted by phone two months after discharge and a semi-structured interview approach was utilised to ask about their functional ability, sleep patterns, concentration levels, social relationships and any support they were receiving. The most frequently reported problems were muscle weakness, fatigue, issues sleeping and financial difficulties. The only mention of nutrition was the fact that one patient was referred to a dietitian for advice on malabsorption syndrome. Moran et al (2005) concluded that "*the follow up service positively contributes to patient outcomes*" (p47).

Cuthbertson et al (2007) undertook a randomised controlled trial to evaluate the effectiveness of ICU follow-up clinics. Patients were recruited from 3 UK hospitals after an ICU stay and randomised into a control or intervention group. Patients in the intervention group were given a self-help physical rehabilitation manual providing an exercise programme for the first three months post ICU discharge. No nutritional information was provided. Patients were followed up at a nurse led clinic at three and nine months after discharge. A total of 286 patients were recruited into the trial and 192 completed a one year follow up. The results showed no benefits to quality of life at 12 months and suggested that future work should focus on early physical rehabilitation (Cuthbertson et al 2007).

Elliot et al (2011) conducted a randomised controlled trial of a home-based physical rehabilitation program. 195 post ICU patients were randomised to receive either standard community based care after hospital discharge or an 8 week exercise program with home visits from a physical trainer, follow-up phone calls and an exercise manual. Outcome measures included the six minute walk test and health-related quality of life scores. The results showed no difference in physical recovery between the two groups. The authors concluded that further research was needed to ascertain the most effective interventions and also determine which patients would benefit from such interventions (Elliot et al 2011). This study focused on exercise rehabilitation and did not include any references to nutritional recovery.

The highlighted rehabilitation strategies during the different stages of the patient's critical illness journey demonstrate the focus on physical rehabilitation. The importance of nutrition in the physical recovery process was highlighted by Griffiths (2002) who stated that "*the period following intensive care is characterized by anabolism, remodelling, restoration and redistribution of the body composition. This is not possible without an adequate nutrient delivery. The right foods are important, but the challenge is not in recognizing the need for adequate nutrition but in enabling the desire, delivery and ability to eat over the prolonged period of rehabilitation*" (p48). Despite this, there is a lack of nutrition specific research in patients after critical illness to determine the optimal nutritional management for this patient group.

1.3 Rationale for study

1.3.1 The researcher's personal and professional interests

The researcher undertaking the current study is a clinical dietitian working within the ICU. Nutritional care *in* ICU has been the focus of many research studies which have looked at the optimal timing, route and type of nutritional support for this patient group. The researcher's dietetic practice has evolved over the years to incorporate the findings from this expansive body of literature. An increasing awareness of the complexity of the nutritional problems these patients face during their ICU stay led the researcher to consider their nutritional recovery after critical illness. The researcher was particularly concerned about patients who were malnourished on admission to ICU and lost more weight as a result of their critical illness and also those who had long ICU stays and were particularly debilitated.

The researcher was aware that there was little reference to the specific dietetic management of patients after critical illness in dietetic textbooks. The most commonly used dietetic textbook, the Manual of Dietetic Practice provides detailed information about dietetic management of a wide range of conditions including diabetes, coeliac disease, inflammatory bowel disease, stroke, pancreatitis and liver disease (Thomas & Bishop 2007). There is a section on dietetic management of critical illness which provides information about nutritional requirements and the most appropriate route and type of nutritional support for critically ill patients.

However, no information is provided about the management of patients after critical illness.

The undergraduate training of the researcher in nutrition and dietetics did not include any information about the dietetic management of patients after critical illness. Recognising that this was over 17 years ago, the researcher questioned five dietetic students from various universities across Scotland. These final year students were undertaking their last 12 week dietetic placement in the hospital where the researcher is employed. The researcher asked the students about their dietetic training related to critical illness. The students all reported that information was given regarding the dietetic management of patients in ICU, but not following critical illness.

Within the hospital, dietetic services are currently provided in speciality areas such as surgery, general medicine or respiratory medicine. Post ICU patients are transferred to their parent speciality and seen by the dietitians who have experience of the nutritional problems specific to that speciality. However they do not necessarily have expertise in the complex problems faced by patients after critical illness. The researcher was concerned that current dietetic management of post ICU patients was limited and the provision of effective nutritional rehabilitation to such a complex patient group presented a challenge.

This awareness and an interest in research led to her involvement with the Edinburgh Critical Care Research group, a multidisciplinary research group within the University of Edinburgh. She carried out a service evaluation that highlighted the nature and extent of the nutritional issues experienced by this group of patients at ward level. A subsequent pilot study, looking at providing an enhanced nutritional package of care to post intensive care patients, identified potential factors that might improve care in this area. The researcher realised that interventions for this patient group needed careful development and evaluation to ensure improvements in patient wellbeing and translation into widespread clinical use. The service evaluation and pilot study are described in more detail below.

1.3.2 Nutritional issues identified from pre-doctoral work

1.3.2.1 Service evaluation

The paucity of research in the area of nutritional rehabilitation led the researcher to undertake a service evaluation to benchmark current dietetic and physiotherapy management between ICU and hospital discharge. The service evaluation looked at the physical and nutritional status of patients during the ward phase of care, to provide information about the patient population at transfer to and during their ward stay. It also examined the provision and content of dietetic and physiotherapy input during this phase of care.

Patients who received more than four days mechanical ventilation in ICU, and were subsequently discharged to a hospital ward, were included in the service evaluation. Patients were excluded if they were a suicide/overdose attempt, had an underlying illness that had an established in-patient rehabilitation service e.g. head injury, transplant, cardiac, stroke or referral to palliative care. Twenty-four patients (12 males: 12 females) met the inclusion criteria and data were collected during a 3 month period from June to August 2006.

A number of nutritional outcomes including weight, body mass index, hand grip dynamometry and anthropometric measurements were collected to assess the patient's nutritional status. In addition, estimated energy and protein requirements were compared against the actual nutritional intake obtained from food record charts to establish whether patients were receiving adequate nutrition to maintain weight. The calorie requirements for each patient were estimated using the Schofield equation (Schofield 1985). This calculation was based on providing sufficient calories to maintain weight i.e. meeting 100% of energy requirements was necessary keep maintain weight. Protein requirements were estimated from work done by Elia (1990). Documentation of the mode of feeding and the impact of diarrhoea, nausea and vomiting on nutritional intake was also recorded.

Results indicated that calorie and protein intakes deteriorated overall during the ward phase, such that patients were at risk of further reductions in weight rather than recovery. Weight loss in this group of patients is often masked by the presence of oedema making weight an unreliable indicator of changes in nutritional status (Downs & Haffejee 1998). For this reason, only the weights of patients on discharge

from hospital were used to calculate body mass index (BMI) and compared to pre-illness BMI. Only 9 out of the 24 patients had both a pre-illness weight and a weight on discharge from hospital to enable BMI to be calculated. The median BMI was lower on hospital discharge compared to hospital admission (table 1).

Table 1: Body Mass Index

n=9	Median (IQR)	
	Admission to Hospital	Ward Discharge
Body Mass Index (kg/m^2)	24.0(19.6-26.5)	20.7(17.3-26.5)

Anthropometric measurements were carried out to provide an indicator of body mass as this method is less dependent on hydration. Measurements are ideally carried out on patients who are able to stand or sit on the side of the bed unaided. Due to the limited functional ability of many of the patients on discharge from ICU, only 11 were able to be mobilised into a position suitable for taking the measurements, it is interesting to note that this had only increased to 16 at the time of hospital discharge. Mid arm muscle circumference measurements at discharge from hospital showed that a quarter of patients showed evidence of nutritional depletion.

Grip strength increased overall from discharge from ICU to discharge from hospital but the median value was less than 50 % of normal. The reliability of handgrip dynamometry in the ICU population has been questioned due to other factors affecting functional impairment such as critical illness polyneuropathy (Douglas et al 2000). If this is the case then the service evaluation may indicate a high prevalence of neuropathy and myopathy affecting patients even at discharge from hospital. Neuromuscular weakness is a major contributor to the high level of disability experienced by this patient group (Lipshutz & Gropper 2013).

The service evaluation highlighted the nutritional deficits which were evident in post ICU patients. A number of organisational issues were identified which compounded nutritional problems. These included limited dietetic resources, with the median number of dietetic visits on a weekly basis found to be less than 2. This resulted in nutritional issues not being identified immediately with subsequent delays in appropriate action. Other problems were noted to result from breakdowns in service delivery. For example, nutritional supplements needed to be prescribed on the drug

kardex, the dietitian then had to order them from catering, supplements then needed to be delivered from the kitchen to the ward fridge by the ward hostess, given to the patient by the nurse and finally actually consumed by the patient. This process was subject to multiple breakdowns, all of which reduced the likelihood of the patient receiving the nutritional supplement.

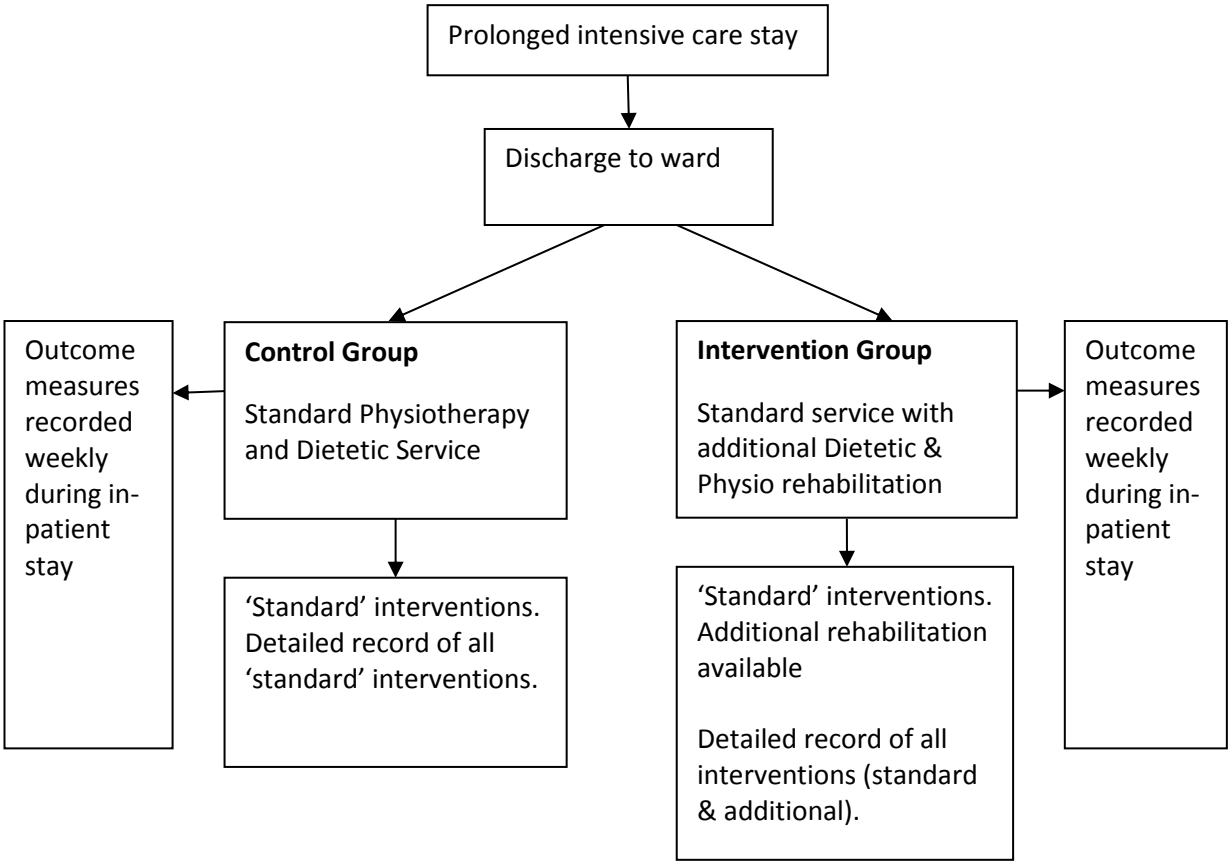
The service evaluation demonstrated that nutritional recovery was suboptimal in patients after critical illness. It also highlighted the complexity of the nutritional issues in this patient group with multiple factors that potentially influence nutritional recovery. These identified factors are not considered in existing literature and no research has been carried out in this area.

1.3.2.2 Pilot study

The researcher went on to undertake a pilot study to look at the feasibility of an intervention to augment nutritional and physical recovery during the ward phase of care. Patients were eligible for inclusion in the study if they had received mechanical ventilation for more than four days. Exclusion criteria included an underlying illness that already had an established rehabilitation service e.g. head injury, liver transplant, stroke or had been referred for palliative care. Ethical approval was obtained from Scotland A Research Ethics Committee and allowed the inclusion of participants unable to give informed consent. In these cases consent was sought from the patient's nearest relative or welfare guardian. If, and when, the participant became competent to give consent their informed consent was obtained.

Patients were approached for recruitment on discharge from ICU and were randomised into one of two groups using a computer generated list. Patients randomised into the control group received standard ward-based physiotherapy and nutritional services. Those allocated to the intervention group received standard ward physiotherapy and nutritional services plus access to additional rehabilitation defined through structured discussion between the appropriate member of the research team and the ward dietitian or physiotherapist and delivered by a 'generic rehabilitation assistant' (figure 1).

Figure 1: Study design



The study piloted the use of a 'generic rehabilitation assistant' (GRA) to deliver additional dietetic and physiotherapy interventions supervised by physiotherapists, dietitians, and medical staff. The number of generic assistants in the UK have increased over recent years and are commonly employed in rehabilitation and intermediate care settings (Pullenayegum et al 2005). In 2000, the Audit Commission reported that "*the redeployment of 'generic assistants', who cover more than one discipline, helps by providing a much more flexible and efficient workforce that fits well with the multidisciplinary focus of rehabilitation and the complex needs of patients and users*" (Audit Commission 2000 p78). However, a report from the NHS Modernisation Agency (2005) highlighted that generic assistants have varying roles, responsibilities, grades, and levels of supervision. For the pilot study the GRA was recruited to an NHS band 4 grading which is an assistant level post that requires an understanding of relevant practice gained from formal training or experience. Appropriate training was provided by the research dietitian and physiotherapist to assistant level in the area of dietetics and physiotherapy. This involved a month of intensive training including formal lectures and assessment of clinical practice.

A key element of this study was the recording of both 'standard' and 'additional input' in both groups to identify key components of the interventions. Figure 2 gives examples of the increased physiotherapy and nutritional rehabilitation. Outcome measures appropriate for use in a clinical ward setting were collected weekly and assessed for their suitability and sensitivity as primary and secondary outcomes (figure 3).

Figure 2: Examples of increased physiotherapy and nutritional rehabilitation

Physiotherapy	**Nutritional**
Supervised strengthening exercises Mobility practice Functional practice e.g. Transfers	Prolonged tube feeding Supervision of oral supplement consumption Assistance at meal times Liaison with kitchen services

Figure 3: Outcome measures

Physiotherapy	**Nutritional**
10m walk test Timed up and go Rivermead Mobility Index Muscle strength	Body Mass Index Anthropometric measurements Hand Grip Dynamometry

Over a 5 month recruitment period 32 patients were eligible for inclusion. Of these 7 were already enrolled in other research trials. Of the remaining eligible patients 3 were discharged from hospital within a few days before being approached, 1 patient refused consent, and 5 were eligible but not approached for logistic reasons. These data indicated 5-6 eligible patients per month and ≥50% recruitment rates were feasible. Consent rates were >90% of approached patients (16 of 17). Eight participants were randomly allocated into each group. Table 2 summarises the demographic details of the two groups.

Table 2: Demographic details of participants

	Control Group (n=8)	Intervention Group (n=8)
	Median (IQR)	Median (IQR)
Gender	6 Male : 2 Female	5 Male : 3 Female
Age (Years)	57.5 (52.8, 70)	67 (44.5, 77.8)
APACHE II*	26 (19.3, 39)	31 (23.3, 42)
Ventilation Days	12.5 (6.8, 22.3)	21.5 (19, 30.3)
Length of ICU stay	16.5 (10.5, 25)	23 (20.5, 33.3)
Length of Ward Stay	15 (11.5, 19.8)	25.5 (21, 32.5)

*Apache II (Acute Physiology and Chronic Health Evaluation II) is a severity-of-disease classification system used in ICU (Knaus et al 1985). A score from 0 to 71 is calculated based on several measurements; higher scores correspond to more severe disease and a higher risk of death.

Both groups had a larger proportion of male participants which is typical of ICU populations. The intervention group were slightly older, had a higher Acute Physiology and Chronic Health Evaluation (APACHE) score (a measure of the severity of disease), received more days of ventilation and had longer intensive care unit (ICU) and ward lengths of stay than the control group.

The service delivery model of a generic assistant working with the already established ward-based physiotherapy and dietetic teams was successful. This model did raise some issues that were addressed during the pilot. These issues included:

- Post ICU patients were cared for on their parent ward so the generic assistant had to integrate into a variety of wards and communicate with multiple health professionals.
- As the patients were cared for in their parent wards, the generic assistant spent large amounts of time travelling between the different wards and to and from the patients.
- The nature of acute illness meant that treatments had to be short and frequent which the generic assistant had to fit in around the normal therapy already being delivered.
- Chaotic discharge planning meant that the generic assistant struggled to ensure that outcome measures were completed prior to discharge.

The nutritional results from the study indicated that patients in the intervention group received a higher frequency of dietetic visits in comparison to the controls. The control group received a median (IQR) of 1.2 (0.6, 2.1) dietetic visits per week. The intervention group received a median (IQR) of 4.9 (3.4, 8.4) dietetic visits per week. A Mann–Whitney test between the groups found that the intervention group received statistically significantly more dietetic (p=0.001) visits than the control group (table 3). This was associated with a trend towards a greater intake of calories and protein in the intervention group across the in-patient stay although numbers were too small for meaningful statistical comparison. Calorie and protein intakes did range widely within the groups with calorie targets more often achieved than protein targets in both groups (table 4).

Table 3: Frequency of Dietetic Visits

	Frequency of treatment delivery (per week)					
	Control Group (n = 8)			Intervention Group (n=8)		
	Median (IQR)	Min	Max	Median (IQR)	Min	Max
Frequency of Dietetic visits per week*	1.2 (0.6, 2.1)	0	3	4.9 (3.4, 8.4)	2.3	9.2

*Statistically significant difference found between groups using Mann–Whitney U-test

Table 4: Average Calorie and Protein Intake as a % of Estimated Requirements

	Control Group (n = 6)			Intervention Group (n=6)		
	Median (IQR)	Min	Max	Median (IQR)	Min	Max
Average Weekly Calorie Intake as a % of Estimated Calorie Requirements	102.3 (83.4,153.8)	79.1	161.7	114.6 (66.4, 144.3)	36.9	163.1
Average Weekly Protein Intake as a % of Estimated Protein Requirements	62.8 (50.7, 91.8)	49	103.9	76.7 (48.1, 96.6)	22.7	130.9

Three months follow up was completed in 13 patients (72%). The 5 missed patients included 3 deaths (2 intervention, 1 control), 1 loss to follow up and 1 non-attendance due to acute confusion (87% follow rate for eligible patients). Two participants were only able to complete selected outcome measures at three month follow-up due to cognitive impairment, a common problem after critical illness

(Jackson et al 2009), and lack of space to undertake physical tests during the home visit.

Table 5: Outcome measures at 3 months post intensive care discharge

Outcome Measure		Median (IQR)	Min	Max
Visual Analogue Scale (Appetite)	Control n=5 Intervention n=5	4.9 (3.2, 7.4) 8.4 (4.9, 9.2)	2.3 3	7.8 9.5
Handgrip Dynamometry (Improvement between baseline and 3 months)	Control n=6 Intervention n=4	21.0 (13.8, 25.8) 13.5 (5.5, 47)	-5.0 5.0	28.0 56.0
Calorie Intake as a Percentage of Estimated Calorie Requirements	Control n=4 Intervention n=5	70.0 (63.1, 95.9) 113.4 (71.9, 113.4)	61.8 70.2	103.6 175.5
Protein Intake as a Percentage of Estimated Protein Requirements	Control n=4 Intervention n=5	68.7 (61.9, 93.9) 90.3 (72.7, 126.1)	61.4 55.0	100.7 150.9

The results showed a trend towards better appetite scores in the intervention group at three months post ICU discharge. This is reflected in the higher median calorie and protein intakes in the intervention group although nutritional intakes did vary widely across both groups (table 5).

Anthropometric measurements were only completed in three control and four intervention participants as it was technically very difficult to obtain baseline measurements in this patient group as many were bed bound during the early phase of ward care. At baseline none of the participants in the control group fell under the fifth centile for mid arm muscle circumference. All four participants in the intervention group fell under the 5th centile which is indicative of protein energy malnutrition. At the three month follow-up three patients in the intervention group had improved mid-arm muscle circumference measurements which no longer fell under the fifth centile.

The results of the pilot study indicated that enhanced physical and nutritional rehabilitation could be delivered by a GRA in conjunction with the standard ward-based rehabilitation. Enhanced levels of physical therapy were achieved and all the additional physiotherapy interventions delivered by the GRA were recorded. The

pilot study demonstrated that in order to meet nutritional targets, especially for protein intake, additional work was needed to develop a range of nutritional strategies for individual patients. The researcher concluded that in order to develop these nutritional strategies a greater understanding of the factors affecting nutritional recovery at patient and at organisational level was required.

Throughout her pre-doctoral research the researcher became increasingly aware of the complex nature of food and the factors that may influence eating. During the service evaluation and the pilot study patients often talked about their bodies, the alterations to their physical appearance after critical illness and it was apparent that patients were struggling to come to terms with these changes. This led the researcher to speculate if the way patients viewed their body after critical illness influenced their relationship with food.

1.4 Purpose of doctoral study

In light of the paucity of literature on nutrition after critical illness and the identified issues from pre-doctoral work, the researcher undertook the doctoral study to elicit patients' experiences of eating after critical illness and develop a theoretical understanding of the processes influencing nutritional recovery. The aims of the study were to provide a comprehensive understanding of the factors influencing nutritional recovery, and the relationship between them, in patients after critical illness; and to develop a model of care to improve the current management of nutrition for patients recovering from critical illness.

As this doctoral study was undertaken to inform future healthcare interventions in nutritional recovery after critical illness, a health services research framework was adopted to ensure that appropriate consideration was given to the development of interventions and the design of their evaluation (MRC 2008).

There are a number of published frameworks to facilitate the process of defining and evaluating interventions and these are described in more detail below.

1.4.1 Use of health service research frameworks

Over the last 15 years a number of health service research frameworks have been published emphasising the need for adequate development of interventions and the design of their evaluation (Bradley et al 1999, Glasgow et al 1999, MRC 2000, van Meijel et al 2004, MRC 2008). The need for these frameworks is supported by the rising costs associated with conducting a trial (Collier 2009), the "*many methodological challenges in evaluating complex interventions*" (Blackwood 2006 p613) and the difficulties in applying the intervention in real life contexts (Bradley et al 1999).

To address these issues Bradley et al (1999) proposed a complex intervention framework that used three levels for defining a complex intervention: the evidence and theory underpinning the intervention, the core tasks and processes associated with undertaking the intervention and the people with whom, and the context within which, the intervention is used.

Another model designed to evaluate interventions is the RE-AIM framework (Glasgow et al 1999). The RE-AIM model has dimensions that assess the impact of an intervention: Reach, Efficacy, Adoption, Implementation and Maintenance. Reach relates to the proportion of the target population that would be reached in the intervention and the characteristics of participants versus non-participants. Efficacy relates to the influence of the intervention on measurable objectives. Adoption pertains to the percentage of other organisations that will decide to utilise the intervention. Implementation refers to the consistency of delivery of the program when applied in real life settings. Lastly maintenance relates to the extent the program is sustained at both patient and organisational level.

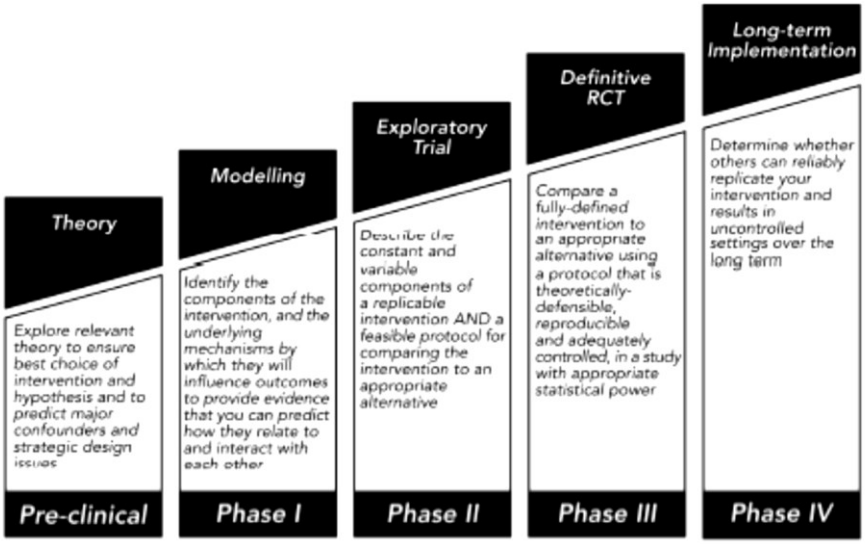
Van Meijel et al (2004) developed a model to facilitate the process of developing and testing complex nursing interventions. The model is composed of four stages: defining the problem, accrual of building blocks such as a literature review and analysis of practice to design intervention, designing the intervention and lastly intervention validation.

One of the most influential health services research frameworks was devised by the Medical Research Council in 2000 and updated in 2008 (MRC 2000, MRC 2008).

The earlier MRC framework was presented as 5 sequential phases: preclinical or theoretical phase, modelling phase, exploratory trial, randomised controlled trial and long-term implementation based on the phases of drug development studies (MRC 2000).

Since then a number publications have highlighted limitations in the framework. Hardeman et al (2005) identified the need for further clarification on how to carry out the review of the evidence and modelling of the framework. Another limitation was the sequential approach to the preclinical, modelling and exploratory phases recommended in the MRC (2000) framework as this was found to be restrictive in practice (Campbell 2007). Work by Campbell et al (2000) identified the need to understand the context of the research, the nature of the problem, the intervention and the evaluation concurrently, not as the stepwise approach suggested by the MRC (2000) guidance (figure 4).

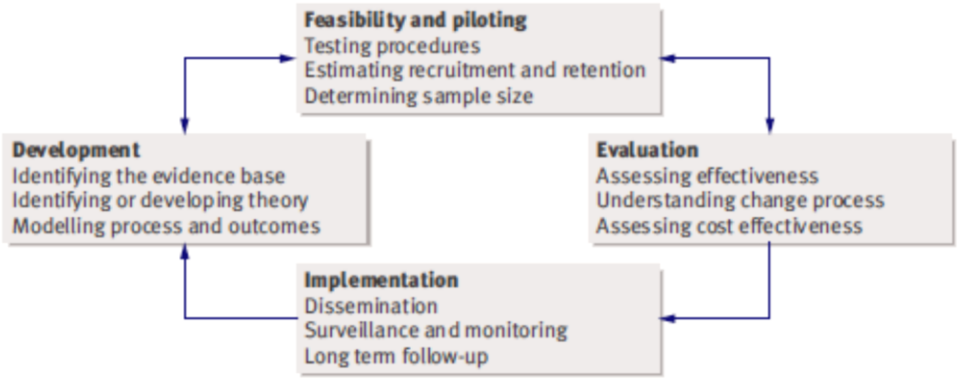
Figure 4 MRC framework for design and evaluation of complex interventions



A further limitation in the MRC (2000) framework was identified by Oakley et al (2006) who highlighted the need to incorporate process evaluation as an integral part of a trial. Oakley (2006) argues that process evaluation "*can help distinguish between interventions that are faulty (failure of an intervention concept or theory) and those that are badly delivered (implementation failure)*" (p413). Campbell et al (2007) also identified the need to adapt interventions to local contexts instead of the standardised approach suggested in the MRC (2000) framework.

New guidance from the Medical Research Council addresses the limitations highlighted above (MRC 2008). The updated MRC (2008) framework describes the interconnectivity between the phases of developing, evaluating and implementing a complex intervention (figure 5). The MRC (2008) provides more details on the key elements of the development and evaluation process recommending that interventions should be developed using the available evidence and appropriate theoretical basis. The interventions should then be tested with pilot studies initially before carrying out an exploratory study and a detailed evaluation (figure 5).

Figure 5 Key elements of the development and evaluation process (MRC 2008)



In recognition of the methodological challenges of designing complex interventions the MRC (2008) framework suggested the use of mixed method strategies in order to surmount some of the issues (Craig et al 2008). Health services research encompasses the full range of research methods including quantitative and qualitative research methods, epidemiology and quality improvement research in order to define and understand the problem and develop an intervention (Campbell et al 2007). Inherent in the design of complex interventions is context and this is addressed in the updated MRC (2008) guidance. Context encompasses cultural assumptions, health care systems and population characteristics. An understanding of context is crucial when designing an intervention as it could influence the effectiveness of the intervention and its applicability to other settings (Campbell et al 2007).

Rigorous trial design is paramount in order to understand the findings. One of the dangers of undertaking a complex intervention for a clinical trial is understanding and interpreting both positive and negative results. A negative result could due to the fact that the intervention was not delivered as it was intended, or one key part was

not delivered hence reducing its effectiveness, or that it was delivered and did not work. To address this issue the MRC (2008) framework suggests incorporating process evaluations into the trial design to explore how the intervention is implemented and facilitate the interpretation of the outcome results (Oakley et al 2006).

Another issue in undertaking a complex intervention relates to measuring outcomes. A single outcome may not have the validity or responsiveness to detect a true benefit. Again a negative trial could mean that there was no patient benefit but it could also mean that the outcome measure lacked sensitivity for that outcome or intervention that has effects across a number of domains (Craig et al 2008).

1.4.2 Adoption of MRC framework

This doctoral study was undertaken as a piece of health services research intended to facilitate the development of a complex intervention to promote nutritional recovery after critical illness. This research draws on the MRC (2008) framework for complex interventions to facilitate the development of an intervention with a sound theoretical and empirical basis.

When developing a complex intervention the MRC recommends addressing the following questions:

- *Are you clear about what you are trying to do, what outcome you are aiming for, and how you will bring about change?*
- *Does your intervention have a coherent theoretical basis which has been used to develop the intervention?*
- *Can you describe the intervention fully, so that it can be implemented properly for the purposes of your evaluation, and replicated by others?*
- *Does the existing evidence suggest that it is likely to be effective or cost effective?*
- *Can it be implemented in a research setting, and is it likely to be widely implementable if the results are favourable?*

(MRC 2008 p4).

The researcher's ultimate goal is to develop a nutritional intervention to promote nutritional recovery after critical illness. The researcher's background work has demonstrated a need for interventions to improve nutritional recovery in post ICU patients and there is a lack of evidence to determine the optimal nutritional management in this patient group. The purpose of this doctoral study was to establish a theoretical basis to develop the intervention. This research aimed to provide an understanding of the factors that influence nutritional intake in post ICU patients which will be used to develop a taxonomy for a nutritional intervention.

The process of nutritional recovery has multiple linked elements including appetite, physical ability to eat, personal preferences and emotional influences. Superimposed on these are the systems that deliver nutrition to patients. If all these form links in a chain that lead to nutritional recovery it is entirely possible that a single break in the chain could disrupt the benefits from all the other elements. Hence, there is a need to understand as many components of recovery in order to develop the best complex intervention.

Understanding both process and outcomes is critical prior to undertaking a trial. This emphasises the need to spend significant time understanding what processes are needed but also what outcomes measures are relevant to patients and how to measure them. This doctoral study forms an important part of this by addressing the development element in the key elements of the development and evaluation process (figure 5). It adds to the evidence base in line with the MRC framework which highlights the need to develop theory prior to further work (MRC 2008). The guidance suggests that too strong a focus is often made on immediately evaluating an intervention without adequate preliminary study of the process in order to understand what needs to be done. This results in trials of limited use due to poorly defined interventions that are difficult to implement in clinical practice. The process of establishing a theoretical basis for the intervention involves an assessment of the literature and evidence surrounding the intervention. "*Interventions aimed at changing behaviour may also require an evaluation of theories of individual and organisation behaviour in addition to informal evidence of beliefs and attitudes that promote or hinder behavioural change*" (Blackwood 2006 p614).

In light of the need to develop a theoretical understanding of the processes that influenced nutritional recovery, a grounded theory approach was adopted in the doctoral study. The appropriateness of this methodology was further justified through an exploratory study which had initially used a case study approach, before realising the limitations of this methodology for the purpose of the study.

The researcher wishes to highlight from the outset that her 'third person' writing style contrasts with the usual qualitative 'first person' approach to writing. This style was adopted by the researcher despite an awareness that by employing a grounded theory approach meant she was a co-constructor of the data. The researcher felt that the use of a more formal 'third person' style focused attention on the patients' perspectives and experiences and emphasised her role and responsibility in the data analysis.

1.5 Summary of Chapter

The purpose of this chapter was to provide a rationale for the doctoral study. It highlighted the complex range of problems experienced by patients after critical illness and identified the need for rehabilitation. It then described the researcher's personal and professional interests and detailed her previous work. This pre-doctoral work identified the complexity of nutritional problems experienced by patients after critical illness and highlighted the need for the doctoral study to develop a theoretical understanding of the processes influencing nutritional recovery in this patient group.

1.6 Structure of Thesis

Following this Chapter 1, Chapter 2 presents the literature reviews to set the scene for the research and describes the role of the literature review in grounded theory. It provides a literature review of three diverse areas which relate to the study, informed by an iterative process with the interpretation of data and emerging themes in later chapters.

Chapter 3 describes an exploratory study that was undertaken as the first stage of this research. It provides a rationale for the study, the methodological approach used and

explores the preliminary findings. The subsequent alterations to the research design of the main study are also highlighted.

Chapter 4 provides a detailed account of the research design of the main study including the theoretical and methodological approaches adopted, use of mixed methods, study sample, ethical considerations and analysis of the data.

A narrative account of the qualitative findings is provided in Chapter 5. This formed the initial phase of the qualitative analysis and details the patients' journey for the first three months after ICU discharge and the issues they experienced.

Chapter 6 presents the quantitative results from the nutritional assessment, food diaries and visual analogue scales. These results are then interpreted and discussed in light of the qualitative findings.

In Chapter 7 the findings and the emerging themes are outlined. The first two themes 'experiencing a dysfunctional body' and 'experiencing socio-cultural changes in relation to eating' emerged in relation to the way patients' experience eating after critical illness. The final theme 'encountering nutritional care delivery failures' emphasises the impact of the organisation on the nutritional experiences of patients after critical illness

Chapter 8 is the concluding chapter and provides recommendations for improving nutritional care for patients after critical illness.

The next chapter (Chapter 2) reviews the literature around nutritional care in hospitals, literature on the body and the socio-cultural effects on eating and how it influences food intake. These areas of literature emerged through the cyclical process of data collection and analysis.

Chapter 2: Literature Reviews

2.1 Introduction

The chapter contains three sections, each of which reviews the literature pertinent to this doctoral study. The first section examines nutritional care in hospital and seeks to highlight the organisational factors which influence nutritional intake. The second section reviews the literature on the body and explores how it may influence the way patients relate to food. The third section examines the socio-cultural effects on eating and how it influences food intake. Finally the chapter explores the findings from a review article that examined patients' experiences of reduced food intake from both a biomedical and social sciences perspective.

2.1.1 Literature review and grounded theory

Intense debate has surrounded the literature review in grounded theory research with the 'purists' arguing against conducting a search of the literature prior to data collection (Glaser & Strauss 1967, Nathaniel 2006). However, the use of grounded theory has been advocated for topics where there has been little research and there is insufficient knowledge (McCann & Clark 2003b). Unless a literature review is undertaken to determine the extent of research in this area, any gaps in knowledge will go unrecognised (McGhee et al 2007). Conducting an initial literature review also provides justification for the study (McGhee et al 2007), promotes the development of 'sensitising concepts' (McCann & Clark 2003b) and 'sets the stage' (Charmaz 2006) for the interpretation of data. It also avoids the danger of the researcher being unaware of pertinent information. As Coffey and Atkinson (1996) highlight "*the open-mindedness of the researcher should not be mistaken for the empty mindedness of the researcher who is not adequately steeped in the research traditions of a discipline. It is after all, not very clever to rediscover the wheel, and the student or researcher who is ignorant of the relevant literature is always in danger of doing the equivalent*" (p157).

2.1.2 Iterative nature of literature review

The three diverse areas of literature evolved from an iterative process with the interpretation of data and emerging themes in later chapters, an approach consistent with grounded theory methodology. As discussed in chapter 1, the researcher carried

out some background work looking at nutritional rehabilitation after critical illness and therefore had already developed some 'sensitising concepts'. Charmaz (2006) argues that it is not possible to approach the data without preconceptions, indeed the notion that any researcher carries out a study without at least some background knowledge is naive (Dunne 2010). Kennedy & Lingard (2006) state that "*researchers cannot avoid approaching the question with a set of disciplinary interests and background assumptions*" (p103) and Cutcliffe (2000) highlights that "*no potential researcher is an empty vessel, a person with no history or background*" (p1480). These sensitising concepts formed the foundation for the initial literature review which focused on examining nutritional care in hospital and the organisational and patient related factors that influence nutritional care. Through the cyclical process of data collection and analysis the concept of the body in illness and how this may influence the way patients relate to food emerged. The literature on the body, illness and food was explored and forms the second section of the literature review. Similarly, through an iterative approach with the data and the emerging concept of sociocultural changes in relation to eating, the literature relevant to this area was examined and forms the third section of the literature review.

2.1.3 Search strategy

Due to the diverse and vast literature surrounding the three highlighted concepts, a formal systematic review of the literature was not undertaken. The review will focus on the key aspects as they relate to this research study with literature identified through electronic search engines such as CINAHL, EMBASE, Medline, Science Citation Index and Science Direct. A number of key words were used to search the databases with the search terms pertinent to the area of interest. For literature on nutritional care in hospital the key words were "nutrition", "malnutrition", "nutritional screening", "nutritional assessment", "nutritional intake", "hospital", "food service", "patient care", "hospital meals". The search terms for the body literature review were "body", "self", "mind", "identity", "appearance", "biomedical approach". For the socio-cultural aspects of eating review the search terms were "food", "eating", "meals", "culture", "food habits", "social facilitation" and "meaning of food". The Department of Health, Healthcare Improvement Scotland and the National Institute for Health and Clinical Excellence publications were also searched. Additional material was found from reference lists in articles and books. Further

refined searches were undertaken to address issues highlighted from the analysis of the data that required further exploration.

Section 1 Nutrition in Hospital

2.2 Overview of section

The purpose of this section was to review the literature around nutritional care in hospital as the researcher's clinical experience and background work had highlighted that this affects patients' nutritional intake. As previously mentioned in Chapter 1, very little work has been undertaken to examine nutrition in patients after ICU, therefore the review is mainly based on the findings from studies and policies relating to nutrition in acute hospital inpatients. It will examine the prevalence, consequences and factors associated with inadequate nutrition, both for the patient and the organisation and highlight what has already been done to improve nutrition in hospital. Finally it will highlight the issues that still need to be addressed.

2.3 Nutrition in Hospital

The provision of effective nutritional care involves *'a co-ordinated approach to the delivery of food and fluid by different health professionals, and views the patient as an individual with needs and preferences. It is the process that determines a person's preferences and cultural needs, defines his or her physical requirements, and then provides the person with what is needed. It follows a person's progress through an illness, by responding to changing nutritional requirements. It involves the monitoring and reassessment of nutritional status at regular intervals, referral for specialist care when appropriate, and good communication with services in the community. Good nutritional care will involve training for staff, carers and patients, and access to information*' (NHS QIS 2003 p17).

Good nutrition is fundamental to patients' well-being (Brogden 2004) yet it is apparent that poor nutritional care in hospital has been an ongoing problem for many years (Dickinson et al 2008, Naithani et al 2008). Patients often experience deterioration in their nutritional status during hospital admission and this can lead to an increased prevalence of malnutrition (Kelly et al 2000).

2.4 Malnutrition

2.4.1 Definition

Malnutrition is a broad term that can be used to describe any state of poor nutrition that can result from insufficient or excessive dietary intake (Holmes 2003). For the purposes of this literature review, the term 'malnutrition' will relate to under nutrition as a consequence of an inadequate intake of protein and energy and/or the effects of acute illness.

2.4.2 The aetiology of malnutrition

Work undertaken by Keys in the 1950's provided an insight into the physiological and psychological effects of semi-starvation. Participants in the study underwent 24 weeks of semi-starvation losing over 25% of their body weight and experienced a range of symptoms including fatigue, apathy, profound weakness, irritability, neurological deficits and peripheral oedema (Kalm & Semba 2005). During periods of prolonged starvation the body preserves muscles mass and adapts to utilising stores of adipose tissue as an energy source (Alberda et al 2006). This chronic starvation state has been termed 'starvation-related malnutrition' (Jensen et al 2010).

An International Guideline Committee recently defined two other types of malnutrition syndromes: 'chronic disease-related malnutrition' when inflammation is chronic and of mild to moderate degree and 'acute disease or injury-related malnutrition' when inflammation is acute and of severe degree (Jensen et al 2010). Aetiology of these two types of malnutrition has come from an increased understanding of the impact of the inflammatory response on nutrition. An acute inflammatory response increases energy expenditure and nitrogen excretion that is only partially reduced by the provision of nutritional support (Zoico & Roubenoff 2002). In critical illness or injury the resulting inflammatory response results in a rapid decrease of muscle mass (Hill et al 1997). In comparison, the inflammatory response in most diseases is chronic and loss of muscle mass is slower although continues over a prolonged period (Jensen et al 2010).

2.4.3 The prevalence of malnutrition in hospital

The problem of malnutrition in hospital was first reported in The United States of America (USA) by Butterworth in 1974. This heralded a number of studies in the USA and the UK which reported a prevalence of 20-50% in medical and surgical patients (Bistrian et al 1976, Hill et al 1977). Since then numerous studies have found a similar prevalence of malnutrition in hospital inpatients (Larsson et al 1994, Nightingale et al 1996, Garriballa et al 1998). Nutritional status has also been shown to deteriorate during hospital stay with one study showing that 75% of medical patients who were well nourished on admission to hospital were shown to have lost weight during their hospital stay (Weisnier et al 1979). Another study by McWhirter & Pennington (1994) demonstrated that two thirds of patients discharged from hospital had lost around 5% of their body weight.

More recent studies have continued to highlight the prevalence of malnutrition among acute care patients across the UK. A study by Edington et al (2000) found that 20% of patients admitted to one of four hospitals across England were malnourished. In Scotland Kelly et al (2000) found that 13% of patients were malnourished on admission to a Glasgow hospital. In addition it was demonstrated that three quarters of the cases of malnutrition were not identified by healthcare staff resulting in a deterioration of nutritional status during hospital stay. Corish et al (2004) reported that 44% of patients admitted to two hospitals in Ireland were found to be malnourished. A survey of inpatients in a hospital in Fife revealed a 14-25% prevalence of malnutrition depending on the criteria used to define malnutrition (Ruxton et al 2008).

2.4.4 The prevalence of malnutrition in specialised patient populations

Studies have also looked at the prevalence of malnutrition in specialised patient populations. Bauer et al (2002) found 76% of oncology patients were malnourished, 52% of colorectal cancer patients were malnourished (Gupta et al 2005) and Dray et al (2005) showed a prevalence of 50% malnutrition in cystic fibrosis patients. The prevalence of malnutrition has also been shown to increase with age with 23% of people under the age of 65 suffering from malnutrition, increasing to 32% in those over 65 (Russell and Elia 2009). One of the few studies which looked at the

prevalence of malnutrition in critically ill patients found that 43% of patients were malnourished on admission to a general ICU (Giner et al 1996). Length of hospital stay and incidence of complications was greater in the malnourished group compared to those who were well-nourished.

However, comparison between all studies looking at malnutrition is difficult due to inconsistencies in the assessment measures for malnutrition, use of different patient populations, and different settings studied (Bavalaar et al 2008). Common measures used to detect malnutrition include body mass index (BMI) calculated from weight and height measurements, however body weight can be affected by the presence of dehydration, ascites or oedema (Jeejeebhoy 2000, Campillo et al 2004), unintentional weight loss which relies on patient recall or accurate measuring (Corish & Kennedy 2000) and biochemical indices such as serum albumin, transferrin and lymphocyte count. These biochemical markers are poor indicators of nutritional status as they are influenced by metabolic stress and medications (Jeejeebhoy 2000). Anthropometric measures such as triceps skinfold and mid-arm muscle circumference are also used to assess nutritional status however measurements are affected by disease status and age (Omran & Morley 2000). In addition reference ranges are not available for the elderly or specialised patient groups (Campillo et al 2004).

Studies that have used similar methods to assess malnutrition employed different cut off points to define malnutrition (Corish & Kennedy 2000). Kubrak and Jenson (2007) reviewed 11 studies that used BMI to assess nutritional status and found that the 'cut off' values to detect the presence of under nutrition ranged from 16kg/m^2 to 29kg/m^2. Similarly a review of 11 studies that used albumin levels to detect malnutrition revealed that each study utilised different serum albumin ranges highlighting the lack of a consistent approach to the identification of malnutrition (Kubrak & Jenson 2007).

2.4.5 Consequences of malnutrition

Poor nutrition has been found to have a negative impact on clinical, functional and economic outcomes as described below.

2.4.5.1 Impact of malnutrition on clinical and functional outcomes

Malnutrition affects every organ system resulting in reduced gastrointestinal (Winter et al 2000), mental (Brozek 1990), and endocrine (Schwartz & Seeley 1997) function and recovery. Acute illness causing sepsis and inflammation exacerbates the loss of lean tissue mass and function (Jeejeebhoy 2000). Malnutrition has also been shown to impair wound healing (Allison 2000) and increase the risk of infection (Lean & Wiseman 2008). Malnutrition is associated with functional impairment characterised by muscle weakness (Watters et al 1993) and a corresponding reduction in handgrip strength (Humphries et al 2002). Ultimately, malnutrition adversely affects recovery from disease and is associated with a significantly higher incidence of complications and mortality (Correia &Waitzberg 2003). Stratton and Elia (2006) reported that malnutrition doubles the risk of mortality in hospitalised patients. Malnutrition in critically ill patients was associated with increased length of hospital stay, increased incidence of complications and a decreased likelihood of being discharged from hospital (Giner et al 1996).

2.4.5.2 Impact of malnutrition on economic outcomes

Malnourished patients have higher hospitalisation costs, on average 24% higher than those who are well nourished (Lim et al 2012). These costs are due to longer hospital stays, on average 1.5 times longer than well-nourished patients (Lim et al 2012), increased use of hospital resources costing the NHS £6000 per patient over a 6 month period (Guest et al 2011) and higher readmission rates (Lean and Wiseman 2008). Public expenditure on disease-related malnutrition in the UK in 2007 has been estimated at in excess of £13 billion per annum (Elia and Russell 2009).

2.4.6 Detection of malnutrition

The terms 'nutritional assessment' and 'nutritional screening' are used interchangeably in the literature (Green & Watson 2005). Nutritional screening is the process of identifying patients who are malnourished or at risk of becoming malnourished whereas nutritional assessment involves the use of a number of measures such as physical examination, dietary history and anthropometric measures to allow a detailed evaluation of nutritional status (Green & Watson 2005). The screening and assessment methods are described below.

2.5 Nutrition screening tools

Routine screening to detect malnutrition has been hindered by the lack of universally agreed criteria to identify it. Therefore there are many screening tools available and these commonly use weight, height, weight history, functional status and clinical condition to ascertain risk or diagnosis of malnutrition (Huhmann & Cunningham 2005). The important factors determining their successful implementation are acceptability to patients, ease of use, validity and reliability (Jones 2002). In addition the tool needs to be sensitive to detect 'risk' and specific to determine those not at 'risk' (Cochrane & Holland 1971).

There are a plethora of screening tools available however the most widely used tool in the UK is the Malnutrition Universal Screening Tool (MUST) which was launched by the British Association for Parenteral and Enteral Nutrition to facilitate the identification of malnutrition in all clinical settings (BAPEN 2003) (Appendix 1). The benefits of this tool are its ease of use however it has limited testing for validity, reliability, specificity and sensitivity (table 6).

Another screening tool called the Subjective Global Assessment (SGA) was proposed by Detsky et al (1984) (Appendix 2). It incorporates historical, symptomatic and physical parameters to ascertain if nutritional status has been impacted by a reduction in food intake or malabsorption, ascertaining the extent of changes to body composition and if illness or disease influences nutrition requirements (Jeejeebhoy 2000). SGA has been found to be effective in predicting complications in a wide range of conditions including patients on dialysis (Enia et al 1993), surgical (Hirsch et al 1991) and liver transplant patients (Hasse et al 1993). This tool has undergone extensive testing for validity, reliability, specificity and sensitivity hence is accredited with the most 'diagnostic value' for acute patient populations (Kubrak & Jensen 2007). The disadvantage of the SGA is that it requires significant training prior to its use (table 6).

Table 6: Screening tools (Adapted from Kubrak and Jensen 2007)

Screening tool	Tool description	Population tested	Inter-rater reliability		Validity	Sensitivity & specificity	Clinical practicality
			Within groups	Between groups			
Malnutrition Universal Screening Tool (MUST) BAPEN (2003)	Assess Body Mass Index, percentage weight loss and acute disease effect Scoring: 0=low risk 1=medium risk ≥=high risk	Outpatients & inpatients (medical, surgical & elderly patients)	Nurses v healthcare assistant (HCA)/ student nurses; HCAs; medical students	Doctors and nurses	Assessed against other tools but agreement varied from poor to excellent	Not reported	Quick and simple to use Practical in clinical setting Directs clinicians in a plan for nutrition care
Subjective Global Assessment (SGA) Detsky et al (1987)	Assess weight loss, dietary intake, gastrointestinal symptoms, subjective physical assessment Rating: A=well nourished B=moderately malnourished C=severely malnourished	Outpatients & inpatients (medical, surgical and specialised patient populations)	Doctors, dietitian	Nurses and doctors; doctors and dietitian	Assessed against clinical indicators ($p<0.001$)	Sensitivity-82% Specificity-72%	Requires training to use Directs clinicians in a plan for nutrition care

2.6 Nutritional assessment

In the acute setting nutritional status is assessed using a variety of measures. These include clinical measurements, biochemical indices, dietary history and anthropometric and functional measures (Kyle et al 2003). However there is a lack of consensus on the best measure as during acute illness all markers of malnutrition lose their specificity (Jeejeebhoy 1990). Body weight is still the most frequently used clinical measurement to assess nutritional status. However, as previously mentioned interpretation of weight can be problematic as it is affected by the presence of ascites, oedema and dehydration (Campillo et al 2004). Biochemical indices such as albumin are poor indicators of nutritional status as they are affected by medical conditions, medications and age (Corish & Kennedy 2000). Anthropometric measures including skinfold thickness, mid arm muscle circumference and functional measures such as handgrip strength can also vary with disease status and age (Jeejeebhoy 2000, Omran & Morley 2000).

2.7 Patient related factors associated with inadequate nutritional intake

2.7.1 Physiological factors

The effects of acute illness or disease have been found to reduce nutritional intake in a variety of ways. Acute illness triggers an inflammatory response which induces metabolic alterations, elevating resting energy expenditure and nitrogen excretion, hence increasing energy and protein requirements respectively (Dupertuis et al 2003). Food intake is also reduced in acute illness or disease and this is associated with the anorexia accompanying the inflammatory response (Jensen et al 2010). Anorexia was noted to be more prevalent in patients who were already malnourished and continued for the duration of hospital stay resulting in a further deterioration of nutritional state (Patel & Martin 2008).

The underlying mechanisms that result in anorexia are not fully understood however it is thought that acute illness activates inflammatory mediators that trigger a systemic inflammatory response (Richardson and Davidson 2003). These mediators, often referred to as pro-inflammatory cytokines, are produced by a number of cells

including activated macrophages and lymphocytes (Plata-Salaman 1989). Cytokines affect central nervous system controls of food intake (Lennie 1999). One of the best described pro-inflammatory cytokines is interleukin 1β which is known to exert a profound depression of appetite mechanisms (Maier et al 1998).

Interleukin 1β also stimulates the release of cholecystokinin (Daun & McCarthy 1993). Cholecystokinin is a neuropeptide that is secreted by the small intestine with feeding. It binds to receptors on the gastric vagus which stimulate the part of the brain that controls food intake (Hameed et al 2009). This results in a reduction in food intake due to feeling full with increased levels of cholecystokinin being associated with greater satiety (Moss et al 2011).

In addition to influencing satiety during a meal, cytokines also affect the initiation of subsequent meals (Lennie 1999). Tumor necrosis factor alpha (TNFα) is thought to suppress vago-vagal reflex circuits in the hypothalamus which results in delayed gastric emptying (Hermann & Rogers 1995). This feeling of fullness increases the length of time before hunger is felt (Richardson & Davidson 2003).

2.7.2 Perceptions of hospital food

There are a number of issues associated with hospitalisation that could influence patients' eating behaviour. Patients' perceptions of hospital food can influence eating behaviour as hospital food has long been negatively viewed as institutional catering (Bender 1984). This unfavourable image of hospital food is pervasive and hence may not accurately reflect the food itself (Cardello et al 1996). This was demonstrated in a more recent study by Naithani et al (2008) looking at patients' experiences of access to food. They found that patients had preconceived ideas about hospital meals and therefore had low expectations about the quality of the food.

2.7.3 Other patient related factors

A number of studies have examined the impact of patient related factors on nutritional intake in elderly patients. Incalzi et al (1996) found that patients who consumed less than 40% of their nutritional requirements reported a higher incidence of anorexia and chewing difficulties. Dislike of hospital food, poor appetite and nausea were the identified patient related factors associated with poor intake in a study by Sullivan and Walls (1999). Kondrup et al (2002) reported that poor appetite and problems with nausea and vomiting were associated with inadequate nutritional intake. A higher prevalence of mood disturbances, anorexia and oral problems such as poor dentition or mouth ulcers were found in malnourished patients compared to those who were well-nourished (Patel & Martin 2008).

However these studies have been criticised due to disparities in calculating of nutritional requirements and definitions of adequate nutritional intake, lack of rationale for explanatory variables and failure to adjust for potential confounding variables (Mudge et al 2011).

A recent study aimed to identify patient related factors associated with reduced nutritional intakes in 134 elderly patients (Mudge et al 2011). The study was a prospective cohort study carried out in four acute general medical wards. Patients were eligible for inclusion if they were aged 65 years or over and had been in hospital for more than 2 days. Patients who were critically or terminally ill or who were receiving artificial nutritional support were excluded from the study.

Dietary intake was measured for one day and nutritional intake was assessed against estimated resting energy expenditure. Potential explanatory and confounding variables were identified through literature review and focus groups with nursing and allied health professional staff. Identified confounders included age, sex, diagnosis, co-morbidities, medications and hospital ward. Explanatory variables included appetite, nutritional status, functional status, delirium, depression, dentition, dysphagia and the need for a modified diet.

Results showed that energy intake was sufficient for resting energy expenditure in 41% of patients and met estimated total energy expenditure in only 8%. Patients with insufficient energy intake tended to be older with multiple co-morbidities and required greater numbers of prescription medications.

Using multivariate analysis they identified that poor appetite, higher BMI, the need for assistance with feeding, a diagnosis of infection or cancer and the presence of delirium were the factors associated with inadequate energy intakes. The researchers also highlighted that traditional nutritional interventions such as the provision of nutritional supplements were unlikely to be effective in improving nutritional intake due to the complexity of the identified factors. They suggested the need for a multidisciplinary approach which acknowledges and addresses the identified barriers although did not provide any further explanation pertaining to the specifics of this approach.

2.8 Organisational factors associated with inadequate nutritional intake

Weekes et al (2009 p325) highlighted that "*the underlying causes of inadequate intake are multi-factorial and multi-disciplinary and may originate in any part of a healthcare organisation from the strategic policy level down to the individual feeding of a patient*". The factors associated with inadequate nutritional intake have been well documented in the literature and indeed many were identified over 30 years ago by Butterworth (1974). These included:

- diffusion of responsibility for nutritional care
- poor communication between medical, nursing and dietetic staff
- lack of nutritional education for nurses and doctors
- failure to assess nutritional status on admission to hospital
- poor observation and recording of nutritional intake
- high proportion of missed meals due to diagnostic tests
- delay in initiating nutritional support
- inadequate provision of nutritional support

More recently, the Council of Europe highlighted a number of issues that lead to the development of malnutrition (Beck et al 2002). These include:

- ambiguity over responsibility for nutritional care
- lack of nutritional education for nurses and doctors
- lack of nutritional information given to patients
- poor communication between healthcare professionals
- failure of hospital management to engage with nutritional care

All these factors mentioned above originate from the organisation and as such are well recognised to negatively impact on nutritional care in hospital. These organisational issues have been demonstrated in numerous studies and are described in more detail below.

2.8.1 Lack of nutritional knowledge

Lack of nursing knowledge relating to nutrition is not a new phenomenon with a study by Kowanko et al (1999) highlighting that nurses lacked nutritional knowledge and without this knowledge were to provide adequate nutritional care. This was supported by Kondrup (2002) who found that a significant factor associated with inadequate nutritional care was nurses' lack of nutritional knowledge. Medical nutritional knowledge has also been identified as poor and has meant that patients do not receive timely nutritional intervention (Norman 2008). A study by Awad et al (2010) highlighted that only 47% of surgical trainees felt that they had adequate nutritional knowledge. Similarly, this lack of nutritional knowledge has also been demonstrated by clinicians in non-surgical specialities (Nightingale & Reeves 1999).

Insufficient training in nutrition has been identified as a problem (Lennard-Jones 1992, McWhirter & Pennington 1994, Holmes 1996) and the National Institute for Health and Clinical Excellence guidelines for nutritional support recommend that all healthcare professionals receive adequate nutritional education (NICE 2006). Lean and Wiseman (2008) suggest that in order to tackle the paucity of nutritional knowledge, undergraduate medical education needs to incorporate a nutrition course into the curriculum to instil a basic nutritional competency into medical graduates.

The British Association for Parenteral and Enteral Nutrition also recognised the importance of adequate nutrition-related training for health professionals in undergraduate and postgraduate courses but also in continuing professional development (Elia and Russell 2009).

2.8.2 Lack of clarity over nutritional responsibilities

Responsibility for nutritional care spans many disciplines including medicine, nursing and dietetics and the role of each profession is not clearly defined (Jordan et al 2003). The danger with this is that all professionals may revoke responsibility creating a 'care gap' (Corish & Kennedy 2000). Poor communication between healthcare professionals further exacerbates the problem and is a barrier to good nutritional care (Lassen et al 2006).

Ensuring that patients were adequately fed was traditionally a nursing role (UKCC 1997) however catering staff, housekeepers and clinical support workers have become increasingly involved in meal service provision (Xia & McCutcheon 2006). Kowanko (1999) demonstrated that problems with food service were related to a lack of clarity over nursing responsibilities in this area. Specifically, issues were identified around responsibility for menu choice, facilitating patients to eat and recording of food intake. In 2007 the Healthcare Commission undertook a survey of inpatients across 165 English hospitals and found 20% of patients did not get the assistance they needed to eat their meals (Healthcare Commission 2007). Other complaints highlighted by patients were poor food choices and food and drinks placed out of reach. Waters (2007) highlighted that many nurses felt that food service was not their responsibility and was left to untrained members of staff. Failure to identify the nutritional needs of patients and insufficient attention to food intake were identified as other contributors to the problem (Elia 2009).

2.8.3 Problems related to hospital meals and dining environment

Many studies have demonstrated that the dietary intake of hospitalised patients is often inadequate. Barton et al (2000) looked at food wastage in an English hospital

and found that more than 40% of hospital food was wasted. It was also identified that patients failed to meet their nutritional requirements and this was attributed to continuing weight loss in hospital patients. Almdal et al (2003) also demonstrated high levels of food wastage in a Scandinavian hospital and found that 60% of patients showed evidence of malnutrition although this was only highlighted by staff in 20% of the cases. A more recent large observational study of food intake in 16290 hospitalised patients across 25 countries found that more than half the patients did not consume all their meals (Hiesmayr et al 2009). In addition, of the patients who ate less than a quarter of their meals, 50% of these did not receive any form of nutritional support to increase nutritional intake. Decreased food intake was found to be an independent risk factor for hospital mortality with mortality highest in the lowest BMI group (less than18.5kg/m^2) (Hiesmayr et al 2009).

The timing of hospital meals has been identified as a barrier to adequate nutritional care with a study by Dupertuis et al (2003) highlighting the length of time between evening meal service and breakfast. In an observational study of inpatients another identified issue was the inability to provide food out with mealtimes (Lassen et al 2006) and Waters (2007) highlighted the need to increase the availability of food over a 24 hour period.

Prolonged periods of fasting have been demonstrated to lead to reductions in nutritional intake (Kowonko et al 2001). Horan & Coad (2000) reported that periods of nil by mouth, unrelated to pre-operative fasting was the second most common cause of missed meals. Interruptions at mealtimes have been shown to affect nutritional intake with doctors ward rounds and nursing drug rounds being the most commonly reported disturbances at meals (Jordan 2003, Hunt 2007). Lack of assistance at meal time was also reported to lead to a reduction in food intake with nurses giving priority to other activities such as documentation or medication (Xia & McCutcheon 2006). This difficulty in accessing meals was also recognised by Age Concern (2006) who found that the majority of nurses did not have time to help patients with eating and advocated the use of trained volunteers to facilitate nutritional intake. Elia (2009) has also highlighted the need to provide assistance

with eating and advocated preventing interruptions during meals, improving the eating environment, provision of energy dense meals and frequent snacks in order to increase nutritional intake.

2.9 Problems relating to nutrition in ICU

A large body of work has focused on determining the optimal timing, route, type and amount of nutritional support for patients in the ICU (Heyland et al 2003, Simpson & Doig 2005, Nguyen et al 2008, Doig et al 2009). However, critical illness is associated with a decline in lean body mass (Griffith and Jones 1999, Reid et al 2004). Contributing to this weight loss is inadequate nutritional intake with ICU patients only receiving 60-80% of their prescribed energy and protein requirements (Engel et al 2003, Binnekade et al 2005, Reid 2006, Cahill et al 2010) These suboptimal intakes result from delays in initiating feeding (Wandrag et al 2011) and feed interruptions due to nausea, vomiting, abdominal distension, large gastric aspirates, tube displacement, investigations and prolonged fasting for procedures (Heyland et al 2003, Reid 2006).

2.10 Problems related to nutritional recovery after critical illness

Although many studies have addressed nutrition issues during ICU stay, there is remarkably little nutrition specific research during rehabilitation. There are no studies that specifically address the barriers to nutritional rehabilitation, or how best to overcome them, during the ward phase of care.

One study explored the adequacy of nutritional intake in critically ill patients during the first 7 days after extubation from mechanical ventilation (Peterson et al 2010). Oral intake was assessed in 50 patients for the first 7 days after extubation. Only 1 patient consumed greater than 75% of their calorie requirements on day 1 post extubation with calorie intakes for the subsequent days remaining suboptimal. The mean energy and protein intake was less than 50% of estimated requirements on all 7 days of the study period. Patients who consumed less than 75% of their calorie

requirements reported that poor appetite and nausea were barriers to eating. The authors highlighted that further research was necessary to identify appropriate nutritional interventions for this patient group (Peterson et al 2010).

2.11 Benefits of improving nutritional intake

Research into the efficacy of interventions to treat malnutrition has focused primarily on the role of artificial nutritional support and not the provision of food as an integral part of nutritional care (Weekes et al 2009). Weekes et al (2009) undertook a literature review to examine nutritional care interventions and their effects on nutritional and clinical outcomes in any adult healthcare setting. Of the 297 papers that were reviewed only two randomised controlled trials and six other trials were found to address the research question, with 99 additional studies providing evidence for part of the research question. The studies were divided into interventions examining nutritional screening, nutritional assessment; individualised nutritional care; meal time environment; assistance with feeding, nutritional monitoring and documentation. The review identified a paucity of evidence to corroborate any beneficial effects on cost or outcome from current interventions designed to improve nutritional care.

A Cochrane systematic review of protein and energy supplementation in elderly patients at risk of malnutrition found that the use of nutritional supplements produced a small weight gain. However mortality was only reduced in those who were undernourished and the use of supplements had no benefits on functional status or length of hospital stay (Milne et al 2009). Patient compliance to oral nutritional supplements, in order to capitalise on the reported clinical benefits, has been questioned (Elia & Russell 2009). Hubbard et al (2012) undertook a systematic review to investigate whether compliance to oral nutritional supplements varies across various healthcare settings and between different patient populations. The review included 46 studies that included data on compliance to supplements and found a mean compliance rate of 78% with hospital compliance rates significantly lower than those in the community. The authors found that age was negatively

associated with compliance with a compliance rate of 67% in acutely ill elderly patients in hospital.

A recent Cochrane review examined the evidence for treating disease-related malnutrition in four different groupings: dietary advice to no dietary advice; to oral nutritional supplements; to dietary advice plus oral nutritional supplements; and to a combination of dietary advice and supplements compared to no additional intervention (Baldwin & Weekes 2011). Forty five randomised controlled studies met the criteria although the authors acknowledged the potential risk of bias in the studies from allocation, blinding, incomplete outcome data and selective reporting. No significant differences between the groups were identified in respect to mortality or morbidity. Results indicated that dietary advice with or without nutritional supplements may have beneficial effects on weight gain, increasing muscle mass and grip strength. The authors highlighted a need for further research that examines the impact of nutritional interventions on nutritional, functional and quality of life outcomes.

2.12 Policies and Guidelines to Improve Nutritional Care

Numerous recommendations and strategies directed at improving nutritional care in hospital have been incorporated into guidelines and policy documents, both nationally and internationally. The Royal College of Physicians (2002) published a report intended to address medical deficiencies in nutritional care. Recommendations from the working party included:

- doctors should be aware of the importance of nutritional care
- doctors should be responsible for ensuring information is documented about the patient's nutritional status
- doctors should be involved in multi-disciplinary teams to treat complex patients requiring nutritional support
- undergraduate and postgraduate medical training should include teaching on clinical nutrition.

The Council of Europe's committee of Ministers has published numerous recommendations on the provision of food and nutritional care in hospitals (Beck et al 2002). The UK is represented on the committee however the recommendations are not mandatory.

In 2003 NHS Quality Improvement Scotland (NHS QIS) introduced mandatory national standards to improve nutritional care in hospitals. The Food, Fluid and Nutritional Care policy included six standards: policy and strategy at health board level; nutritional assessment and screening for undernutrition; the organisation of catering services and the planning of menus; delivery of food at ward level; communication between staff, patients and carers; and education and training for staff.

National compliance was assessed in 2005 with 17 health boards visited and focused on three of the standards: policy and strategy; nutritional assessment and screening; and education and training for staff. A report of the findings and recommendations from the national review was published (NHS QIS 2006) and a summary is provided in table 7.

Table 7: Findings and recommendations from NHS QIS report (2006)

Standard	Findings	Recommendations
1. Policy and Strategy	All NHS Boards have started the process of developing and implementing a nutritional care policy and strategic plan. All NHS Boards have nutritional care groups. Only a few NHS Boards have a formal clinical nutritional support team with the required membership in place. There is a lack of specialist nutrition nurses. Clinical nutritional support teams are not routinely accessible to all patients who need this service.	NHS boards need to develop, finalise, implement and monitor nutritional care policies/strategic plans within agreed timescales. NHS boards should assess the policy and strategic plan in line with the Board risk management strategy. NHS boards should ensure nutritional care groups have the required membership. NHS boards need to urgently address the lack of formal clinical nutritional support teams and specialist nutrition nurses.
2. Assessment, Screening and Care Planning	Local evidence of thoughtful and careful nutritional care practice. Limited recording of nutritional information within 1 day. Validated screening tools have been implemented in some ward areas with lack of consistency in recording of this information. Limited development of a multidisciplinary care plan which includes specified nutritional information. Discharge planning does not routinely highlight patients nutritionally at risk or ensure follow-up in the community.	NHS boards should ensure that all assessment, care planning and discharged documentation incorporates required nutritional information. NHS boards should implement validated screening tools across appropriate ward areas. NHS boards should establish, through the Knowledge and Skills Framework (KSF), core nutrition knowledge and skills for assessment, screening and care planning
6. Education and Training for Staff	Staff demonstrated an awareness of the importance of nutritional care. A range of in-house training courses have been developed. Most Boards do not have a co-ordinated and structured approach to the provision of nutrition education and training across the organisation.	NHS boards should develop and implement a Board education and training programme. NHS boards should share knowledge, experience and good practice in developing and implementing nutrition courses. Develop core nutritional competencies. Review the nutritional care component of postgraduate training with emphasis on recognising the serious consequences of over and undernutrition.

NHS QIS (2006) found that Scottish health boards were working towards implementing the standards however progress was slow and it was likely to take many years before there would be a marked improvement in nutritional care across Scottish hospitals. In 2007 a collaborative programme to facilitate further improvements in nutritional care across NHS Scotland for a three year period was organised by NHS QIS. The stakeholders NHS Education for Scotland, Health Facilities Scotland and NHS QIS formed part of the Improving Nutritional Care Programme (INCP) to provide an integrated approach to nutritional care across Scotland and support NHS staff to implement the Food, Fluid and Nutritional Care in Hospital Standards. The key outputs from the INCP are summarised in table 8.

Table 8: Key outputs from the INCP

Lead Organisation	Output
NHS Education for Scotland	A capability framework and educational initiatives to ensure that all healthcare professionals involved in the provision of food and fluid have the necessary knowledge, skills and capability to optimise nutritional care.
NHS QIS	A practice development programme of work, building on the issues identified during the first review against the standards.
Health Facilities Scotland	A monitoring tool to support delivery of the national catering and nutrition specification for hospitals in Scotland - Food in Hospitals A nutrition analysis database launched across NHS Scotland in 2010
NHS QIS	A further review of performance against the remaining The Food, Fluid and Nutritional Care in Hospital standards (3, 4 and 5) in 2008–2009 and progress against standards 1, 2 and 6.
NHS Education for Scotland	Development of educational resources to support and develop NHS staff who provide nutritional care, including websites and training programmes. They have supported the development of a nutritional care and fluid module for foundation level doctors. This work, developed by Dr Fred Pender (Fellow in Medical Education, University of Edinburgh), was to be incorporated into the Doctors Online Training System (DOTS).

The Scottish government funded the appointment of Nutrition Champions in each NHS board in Scotland to lead and support these initiatives at local level. The second NHS QIS review of the national standards in nutritional care was undertaken in 2009. Overall, the review demonstrated that NHS boards had progressed with implementing the recommendations. Universal achievements included the incorporation of nutritional care in job/personal development plans and establishment of a structure to facilitate reporting of nutritional issues to the board. Implementation of nutritional screening and care planning has been achieved by the majority of NHS boards in Scotland. Planning and implementation of care for patients with complex nutritional needs has been achieved by most NHS boards (NHS QIS 2010).

Following on from this report, further work by the Improving Nutritional Care Programme focused on improving nutritional care for adults at risk of malnutrition in three areas. The first identified area was the continuation of good practice in nutritional care by improving the efficacy of protected mealtimes and training volunteers to assist patients at mealtimes. The second area was supporting improvements in nutritional care for patients with long term conditions and the third area addressed transitions from hospital to care home by aiming to improve communication relating to nutritional care (Health Improvement Scotland 2012 p3).

The final report from Healthcare Improvement Scotland (formerly NHS QIS) acknowledges that "*we are still on a continuing journey towards reliable systems and processes to ensure that we're getting nutrition right for every person every time. Nutrition must therefore remain a national and local priority for Scotland*" (Health Improvement Scotland 2012 p3).

England has not adopted nutritional standards; guidance is voluntary and therefore health boards are not formally assessed for compliance to the recommendations (McKinlay 2008). The National Institute for Health and Clinical Excellence published guidelines for nutritional support. The recommendations were based mainly on expert opinion or best practice as the research evidence was scant and provided by studies with small sample sizes. The guidelines recommend that all

patients in hospital should be screened and monitored regularly for malnutrition and highlight the importance of choosing the most appropriate route and type of nutritional support (NICE 2006).

The Department of Health has published a number of documents focusing on improving nutritional care in hospitals. Consultation with patients carried out for The NHS Plan (DH 2000a) identified problems with food quality and structure of meals in hospital. The 'Better Hospital Food Programme' was detailed in the NHS Plan (DH 2000a) and proposed a number of standards to ensure the provision of quality food. These standards included recommendations for the frequency of meals and snacks, availability of food 24 hours a day, a suggestion to move the main meal to the evening, adoption of a new NHS menu design, menus that meet the needs of the population group and have been analysed for nutritional adequacy by a dietitian.

In 2004 the Better Hospital Food Programme (DH 2004a) introduced protected mealtimes. The purpose of a Protected Mealtime Policy was to minimise interruptions at mealtimes, facilitate an environment conducive to eating and provide patients with necessary assistance at mealtimes. This initiative was supported by a number of professional organisations including the Royal College of Nursing, the British Association of Parenteral and Enteral Nutrition and the Hospital Caterers Association. The Better Food campaign was terminated in 2007 by the Department of Health and replaced by a Nutrition Action plan (DH 2007). It defined five key priorities for action: raising nutritional awareness; improving nutritional education and training; ensuring clear nutritional guidance; promoting nutritional screening and clarification of nutritional standards.

It is apparent from this review that there are numerous publications promoting the need for effective nutritional care in hospital. The key themes from these include:

- nutritional screening and regular monitoring to highlight risk of malnutrition
- provision of a nutritional plan with clear documentation
- importance of hospital food
- instigation of timely and appropriate nutritional support

- education and training on nutrition for all healthcare professionals

However, as reported by McKinlay (2008), the issue is not a paucity of publications but actually translating these reports into action. This argument was supported by Guest et al (2011) who stated that "*malnutrition is often under-recognised and under-treated in the UK even though several national guidelines for detecting and managing malnutrition are available. However, to be effective these guidelines need to be implemented and this is not currently the case in many parts of the UK*" (p422). Gibbs et al (2012) highlighted that it has become increasingly common for these policies to be implemented without a sufficient review of the evidence to determine the clinical benefits or detrimental effects from the recommended interventions. Additionally, integrating these strategies into clinical practice will have an impact on staffing and resources (Gibbs et al 2012).

2.13 Summary of section 1

Nutritional care in hospitals has been the focus of much attention since a high prevalence of malnutrition was identified. Many studies have demonstrated that a number of organisational and patient related factors contribute to inadequate nutritional intake in hospital. The deleterious consequences associated with malnutrition have resulted in a number of guidelines and standards to promote effective nutritional care in an effort to address this problem, however malnutrition is still prevalent in UK hospitals.

Post ICU patients are at a higher risk of malnutrition due to the effects of acute illness and inadequate nutritional intakes in ICU. None of the identified studies specifically explored the factors that influence nutritional intake in patient after critical illness. It is hypothesised that many of the previously identified organisational factors will also affect nutritional intake in post ICU patients, however the effects of critical illness are wide ranging and complex and it is postulated that there may be other factors which impact nutritional intake.

Interestingly, a recent protocol for a Cochrane systematic review which plans to assess the effects of supportive interventions for enhancing dietary intake in malnourished or nutritionally at-risk adults stated that "*the factors that influence our experiences with food are complex and nutritional care interventions aimed at the management of malnutrition or nutritional risk may need to address more than the provision of calories. The biological and symbolic dimensions of food are inseparable and a socio-anthropological perspective suggests an intimate yet dynamic relationship between consumption of food and perceptions of self ..... In severe illness, coping mechanisms, sense of body image, value of social networks and support, and personal symbolism may all be affected and food may take on new meaning. Overall, this represents a challenge to health professionals and merits a deeper understanding of what really impacts on our experiences with food*" (Gibbs et al 2012).

Reflecting the complexity of factors that influence nutritional intake, the next two sections of the literature review explore the body, self and identity and how this affects the way patients relate to food and the socio-cultural aspects of eating.

Section 2 The Body, Illness and Food

2.14 Overview of section

The previous section has described a health service evidence based view of the nutritional challenges faced by patients during illness. The next section explores the sociological literature around the body in illness and how this may influence the way patients relate to food. The literature around 'the body' was reviewed through an iterative approach with the data, consistent with a grounded theory approach, as the concept of experiencing a dysfunctional body emerged. The literature review focuses on the concept of biographical disruption as a result of illness and examines the impact of an altered body, self and identity on patients' relationship with food. The final part of the section explores how patients experience their body in an environment which is renowned for treating the physical body.

2.15 Introduction

The literature on the body is vast and varied describing the physical body, the body as a symbol of society, the experiential body and the body as a product of power and knowledge. Williams and Bendelow (1998) highlight the many different aspects of the body and suggest the body is in fact "*all of these things and much more besides"* (p2). This review will focus on the work of Bury (1982, 1988, 1991) and Charmaz (1983, 1991, 1995) and explores the concepts of biographical disruption and body, self and identity. It should be noted this area of work is based primarily on accounts of chronic illness. However, given the extent and complexity of problems faced by patients after critical illness, it could be hypothesised that Bury's construct of biographical disruption is applicable to this patient group. Differences in illness progression i.e. the likelihood of deteriorating health in chronic illness and improvements in functional ability in post ICU patients may influence the timing and effects of the different aspects of biographical disruption.

2.16 Biographical disruption

Bury's (1982) work on biographical disruption offers a fundamental understanding of lay experiences of illness (Lawton 2003). The work, which is based on findings from interviews of individuals diagnosed with rheumatoid arthritis, details an approach where the development of chronic illness is perceived as a disruptive event; a biographical disruption (Bury 1982). Illness is an experience where "*the structures of everyday life and the forms of knowledge which underpin them are disrupted*" (Bury 1982 p169). Bury (1982) argues there are three connected aspects to disruption in chronic illness:

- The disruption of taken-for granted assumptions and behaviours, the breaching of common sense boundaries.
- Profound disruptions in the explanatory systems normally used by people, such that a fundamental re-thinking of the person's biography and self-concept is involved.
- The response to disruption involving the mobilisation of resources.

Each aspect of disruption is discussed below.

2.16.1 The disruption of taken-for-granted assumptions

Bury (1982) describes the disruption of taken-for-granted assumptions and behaviours in terms of a "*what is going on here*" stage, or "*attention to bodily states not normally brought into consciousness and decisions around seeking help*" (Bury, 1982 p169). Critical illness is associated with a wide range of physiological changes such as weight loss, fatigue, joint stiffness, pain, muscle weakness (Griffiths & Jones 1999). The researcher postulates that critical illness, like the onset of chronic illness, creates an awareness of a normally taken-for-granted body (Leder 1990). Nettleton and Watson (1998) highlight that we are not normally conscious of our bodily actions as we carry out our everyday tasks. However, in illness or pain this self-forgetful state is lost and we "discover" our body in its dysfunctional state (Van Manen 1998). Chronic illness also disrupts the sense of unity between body, self and identity (Charmaz 1983, Charmaz 1995).

2.16.2 Disruption in explanatory systems

Bury (1982) reports that disruptions in normal explanatory systems involve a re-thinking of the individual's life history and self-concept. The rheumatoid arthritis sufferers searched for the meaning of events. The concept of meaning is further developed and classified in terms of its 'consequence'; the impact of symptoms on everyday life and 'significance'; the imagery and associations attached to a particular condition (Bury 1991). Patients also questioned "why me?", "why now?" and tried to connect past life events to the cause of the illness. Associated with this was the realisation that biomedical explanations and medical interventions were limited, particularly in relation to learning to live with rheumatoid arthritis. It could be speculated that the nature of disruption elicited by critical illness is potentially greater in light of the sudden onset of critical illness, the biographical interruptions associated with 'unreal experiences' nightmares and hallucinations and the unknown length and extent of the recovery process.

2.16.3 The response to disruption

In chronic illness Bury (1982) argues that the need to understand the cause of the illness is synonymous with the need to understand the meaning. Bury (1988) identified two types of meaning in chronic illness: the 'consequences' of illness i.e. the impact of the symptoms on everyday life, and the 'significance' of illness i.e. the images associated with an illness. Therefore the response to disruption involves the mobilisation of material and cognitive resources. It is the area of cognitive processes that has been the focus of further research, highlighting their influence on coping and adaptation strategies (Groarke et al 2005, Gould et al 2010). Bury (1991) argues that coping in chronic illness refers to "*the cognitive processes whereby the individual learns how to tolerate or put up with the effects of an illness*" (p460). In critical illness the researcher postulates that the sudden onset of critical illness and resultant after effects may hinder the adoption of coping and adaptation strategies. In this sense the impact of critical illness on the individual's sense of identity and self-worth may be more profound.

The next section will focus specifically on illness and the disruption to body, self and identity. "*The body is more than just an object to be decorated and enhanced. It is more than a physiologic organism functioning according to a prescribed genetic code. It is more than a container of the self. It is more than a mediator between the self and the world. It is, as Merleau Ponty (1962) states, the embodiment of who we are. The self becomes what it is through body. The body is the self's representative in the world*" (Corbin 2003 p258). The disruptive effects of critical illness will have a major impact not just on the body but also on self and identity. The concepts of self and identity are described in more detail below.

2.17 Self and Identity

"*The body is central to both the experience and feelings associated with illness (self) and in the social processes involved in its management (identity)*" (Kelly & Field 1996 p251). Self is impacted by identity in response to social interactions with others. This is a continuous process with self being constructed and reconstructed due to bodily changes (Kelly & Field 1996).

2.17.1 Self

Self is defined as" *the set of meanings we hold for ourselves when we look at ourselves. It is based on our observations of ourselves, our inferences about who we are, based on how others act toward us, our wishes and desires, and our evaluations' of ourselves*" (Stets & Burke 2003 p130). Howson (2004) argues that who we are i.e. our self and our body are interrelated. In this sense for post ICU patients the effects of critical illness on the body will impact on self. A study by Charmaz (1983) looked at the effects of suffering as a result of chronic illness and the impact on self. Charmaz (1983) found that people suffered from: impaired ability; social isolation; being undermined and burdening others and argued that these identified sources of suffering erode self. The sources of suffering were found to impact on self with the different sources often inter-related. For example loss of bodily control as a result of impaired ability lead to losses of self, social isolation was associated with loss of self and social isolation occurred as a result of leading a restricted life due to impaired ability. The undermining of self occurs as a result of negative interactions with others. Charmaz (1983) highlighted that the stress of chronic illness on family members means that they are not in a position to give positive images of self to the ill person and may undermine them. This can spiral into loss of hope and acceptance of a discredited self which raised concerns about becoming a burden for others. The issue of being a burden was associated with a change of identity from being someone who was previously defined by their activities or interests to becoming someone who is no longer able to carry out these and therefore has an increased dependency on others.

Chronic illness displaces preconceptions about the relationship between body and self and severs the holistic nature of body and self (Charmaz 1991). In order to maintain the unity between the body and self when living with illness people deal with it in different ways: by ignoring it when other aspects of life are perceived as more important; striving to reduce the impact of it by controlling its effects; struggling against it or embracing it (Charmaz 1991).

Another way people deal with chronic illness is to adapt to impairment. Charmaz (1995) focused on this process of adaption in a study which explored the relationship between body, self and identity. *Identity is the "meanings one has as a group member, as a role-holder, or as a person*" (Stets & Burke 2003 p132.) Charmaz (1995 p657) defined adapting as "*altering life and self to accommodate to physical losses and to reunify body and self accordingly*". Charmaz argues that the process of adaption has three phases: experiencing an altered body; coping with changes in bodily appearance; and changing identity goals. Individuals may move through the stages quickly in a cyclical process, others may remain at one phase for long periods. The three phases are described in more detail below.

2.17.2 Experiencing an altered body

Individuals suffering from a chronic illness become aware of the changes to their body and the impact that these changes have on daily life. There is a new awareness of a body that has previously been taken for granted and comparisons are made between the body prior to illness and the newly experienced altered one. This altered body impacts negatively on self with some experiencing a fundamental disruption of body and self. These bodily changes are also associated with negative emotional responses such as anger, regret, guilt and shame. It could be speculated that for the post ICU patient there would also be an awareness of a body that had undergone considerable changes as a result of critical illness resulting in a fracturing of body and self.

2.17.3 Coping with changes in bodily appearance

Suffers of chronic illness try to minimise the impact of changes to bodily appearance on their life and social relationships. When this is no longer possible gender differences were noted as men tended to withdraw more socially than women. Women were more inclined to manage their appearance to cope with changes in bodily appearance. Again it could be hypothesised that a similar scenario would occur for post ICU patients who can experience numerous changes to bodily appearance including weight loss, muscle wasting and hair loss (Robson 2003).

2.17.4 Changing identity goals

Charmaz (1995 p659) defines identity goals as "*preferred identities that people assume, desire, hope or plan for*". Bodily changes precipitate changing identity goals and this in turn is influenced by personal emotions and social relationships. Charmaz (1995) argues that the culmination of this process and a reclamation of a new unity between body and self comes from surrendering to the illness and accepting that an ill body is part of who one is.

2.17.5 Identity

Identities are the public and shared parts of people (Kelly & Field 1996). Williams (1984) highlights that it is through social relationships that identities are established stating that "s*ocial relations are the place in which a sense of identity is developed and constrained, nurtured and broken*" (p187). Work by Kelly (1992) explored the experiences of ulcerative colitis patients who underwent a major surgical procedure, a total colectomy and formation of an ileostomy. Patients experienced an awareness of self as a result of a changed bodily appearance and function associated with surgery and ileostomy formation and there was also a tension between self and public identity. Recovery involved not only adapting to an altered physiology, but also coming to terms with the impact that bodily change had on self and their social identity. This realignment of identity was further compounded by the fact that the ileostomy could be hidden, thus allowing the person to appear 'normal' yet the appliance could fail thereby exposing the concealed identity. It is speculated that for post ICU patients similar issues would be experienced as patients cope with bodily changes, the impact this has on their daily lives and interactions with others.

Work by Goffman (1963) introduces the concept of a spoiled identity or stigmatised identity and characterises it as follows: "*The central feature of the stigmatised individual's situation in life can now be stated. It is a question of what is often, if vaguely, called `acceptance'. Those who have dealings with him fail to accord him the respect and regard which the un-contaminated aspects of his social identity have led them to anticipate extending, and have led him to anticipate receiving; he echoes this denial by finding that some of his own attributes warrant it*" (Goffman 1963

p19). In essence a spoiled identity is where an individual displays evidence of characteristics that are unacceptable to themselves and significant others.

A study by McIntosh and McKeganey (2001) explored identity and recovery from drug use. The concept of spoiled identity was evident in the accounts from recovering drug addicts and had a negative impact on self and was evident by expressions of dislike for the person they had become. Recognition that their drug related identity was unacceptable led to a sequence of events that culminated in the individual reassessing their circumstances and sense of self. Work by Hinsley and Hughes (2007) explored the impact of cachexia on body image in patients with advanced cancer. Altered bodily appearance was found to have a negative effect on other aspects of embodiment such as emotions, spirituality and social relationships.

2.17.6 Body, self, identity and food

A few studies have reported a link between body, self, identity and food intake. Van Knippenberg et al (1992) highlighted that the relationship between poor nutritional intake associated with weight loss in cancer patients and the physiological impact of disease, the psychological impact of surgery and psychosocial factors was unclear and postulated that the three may be interrelated. Wainwright et al (2007) explored the experiences of patients who underwent surgery for oesophageal cancer and described how they learned to eat again. The findings highlighted that patients had to adapt to the physiological changes after surgery but also changes to self and social consequences of their spoiled identity. The authors concluded that "*the process by which we make sense of physiological change through social interaction also influences the recovery of physical performance, including appetite and food consumption*" (Wainwright et al 2007 p760).

As previously highlighted there is no research that has specifically looked at the effects of critical illness on the body, self and identity. However, it could be hypothesised that a key significant life threatening event i.e. the onset of critical illness, resulting in profound bodily changes and a variable duration of altered health that in many cases include elements of a 'chronic illness' due to the protracted effects

on functional ability, would impact on self and identity. There is a paucity of work that has explored the possible interrelations between the physiological consequences of illness, the effects on self and identity and the impact on nutritional intake.

It is also apparent that the body is not a passive entity and it reacts to experience. The final part of this section focuses on patients' experiences in a care environment that has been renowned for treating the physical body.

2.18 Impact of treating the 'physical body'

It is well recognised that the National Health Service (NHS) is entrenched in biomedicine with a focus "*not on general well-being, nor individual persons, nor simply their bodies, but their bodies in disease"* (Hahn and Kleinman 1983 p312). This approach contrasts with current policy which emphasises the importance of patient centred care which is *"respectful, compassionate and responsive to individual patient preferences, needs and values*" (Scottish Government 2007 p42).

Despite the instigation of policy, culture change is slow and it could be argued that a biomedical approach where disease is expressed in terms of derangements of underlying physical mechanisms, and disregards the patient's experience of suffering and illness is still evident in current practice (Goldenberg 2006). This approach reduces the issues patients face to disordered physiology and largely ignores psychological or social information (Littlewood 1991).

This is highlighted in a number of classic studies including work by Jeffery (1979) who observed staff in hospital casualty departments and found that patients were classified into 'good' and 'rubbish' patients, with the latter having social or psychological issues. Similarly, Press (1990) identified that healthcare workers felt that their time and resources were inappropriately utilised in attending to social issues. Becker (1993a) also described how medical students referred to some patients as "crocks" as they had no detectable physical pathology yet were time consuming as they presented with multiple psychosomatic complaints. A more recent study by Oloffson et al (2005) highlighted the influence of the classic medical

model in an interview based study of stroke patients where patients were viewed as passive entities, dependent and 'objects' for care. For the post ICU patient it could be argued that the physiological and psychosocial effects of critical illness override the presenting illness. A study by Field et al (2008) revealed the myriad of issues that post ICU patients encounter on the ward and the need for a patient centred approach to effectively manage the physical, psychological and emotional problems faced by this patient group.

2.19 Summary of section 2

The literature relating to the body provides an understanding of bodily experience in illness. The concepts of self and identity highlight the importance of integrating the physical, psychological and social factors which impact on the way the body is experienced. This area of study has been from accounts of chronic diseases and there is a need for more work to be done in acute/critical illness to determine its impact on body, self and identity. Furthermore, there is a paucity of evidence that examines how patients' experience their body after critical illness and the impact of this on their relationship with food.

The next section will review the literature relating to the socio-cultural determinants of food intake. It is hypothesised this may provide another factor which influences patients' experiences of eating after critical illness.

Section 3 Socio-cultural Aspects of Eating

2.20 Overview of section

The purpose of this section is to review the literature around the socio-cultural aspects of eating. It will explore the impact of socio-cultural influences on what we eat, who we eat with and the meanings we attach to food. A search of the literature was undertaken from free living, hospital and ICU populations.

2.21 Introduction

Crotty (1993 p109) highlighted that "*the act of swallowing divides nutrition's 'two cultures', the post swallowing work of biology, physiology, biochemistry and pathology, and the pre-swallowing domain of behaviour, culture, society and experience*". Nutritional science focuses heavily on the pathophysiological elements of nutrition, the post swallowing aspects, with little work being done on the pre-swallowing elements, the socio-cultural aspects of eating (Crotty 1993). Shepherd (1999) argues that food intake is "*.... not determined entirely by physiological or nutritional need, but is also influenced by social and cultural factors. The culture in which individuals are brought up has a very strong influence on the types of choices made, and social interactions will have a profound effect on our views of foods and our eating behaviour*" (p807).

2.22 Eating habits

Eating routines provide a structure for daily living and are integrated into work, family and leisure activities (Jastran et al 2009). Jastran et al (2009) argues that eating habits are shaped by social and cultural factors which determine the appropriate timing, settings and type of food that constitutes meals and snacks. "*People's attachment to certain eating habits reveals the social relationships and cultural identities of which they are a product*" (Murcott 1982 p209). Classic work by Charles and Kerr (1988) highlighted the historical importance of a 'proper meal' in British culture. This meal comprised of cooked meat and two vegetables and was distinguished not only by its composition but by everyone in the family being present and appropriate behaviour at the table. In addition to learning socially acceptable behaviour, children also acquired cultural tastes (Warde & Hetherington 1994). Eating habits in the UK have evolved since then with pre-prepared convenience food usage rising and more food being consumed out with the home (Cheng et al 2007).

2.22.1 What we eat

Delormier et al (2009) argued that eating does involve an element of choice but choice is coloured by socio-cultural influences. Mennell et al (1992 p9) highlighted

that "*taste is culturally shaped and socially controlled*". However within any socio-cultural context people may express a variety of likes and dislikes for certain foods (Douglas 1978).

Parental influence governs the type and amount of food that should be eaten during childhood (Dietz 2001). Parental restriction of foods high in fat and sugar in accordance with cultural healthy eating messages has been demonstrated to induce increased consumption of these foodstuffs when they are made available (Fisher & Birch 1999). Family mealtimes have been shown to have a positive effect on eating habits as children who eat with their family consume a higher proportion of fruit and vegetables, less fizzy drinks and have lower fat intakes (Gillman et al 2000). Work by Lau et al (1990) highlighted that parental influence impacts not only on their children's food habits at home but also persists during college years.

In adulthood food intake is influenced by internal and external controls (Lupton & Chapman 1995). This internal regulation of food intake is related to expressions of the 'civilised self'. Work by Elias (1978) described this civilising process where individuals curb natural impulses and display a self-awareness of what is deemed culturally appropriate. Part of this civilising process influences the way certain foods are viewed. Healthy or low fat foods are perceived as suitable to eat as these are seen as good and civilised foods. Foods that are high in fat or sugar are viewed as bad and are associated with self-indulgence.

External regulation of food intake is governed by health promotion and medical advice (Lupton & Chapman 1995). Based on the premise that consumption of healthy foods is associated with good health, unhealthy dietary choices have been correlated with an increased risk of some cancers, cardiovascular disease and diabetes; public health advice on diet is derived from this research (Lupton 1996). Lupton (1996 p81) goes on to state that "*.... people are highly aware of the relationship routinely established in nutritional and biomedical discourses between food and health states, and seek to control their diet so that they conform to the imperatives of good health rather than eating the food that they may prefer for its*

taste". This was demonstrated in a study by Murcott (1993) where the participants used scientific terminology when discussing healthy foods and advocated the consumption of these even if other foods were deemed more enjoyable. The study also highlighted the influence of public health advice as many participants had altered their diet in order to achieve the associated benefits to health.

However healthy eating messages do not dictate eating practice alone, as evolving cultural practices within a population means food beliefs change and influence food intake (Lupton 1994). Work by Fischler (1980) describes the process that drives the changes as an 'omnivore's paradox' where an individual expresses a desire to try new, diverse foods yet exhibits a sense of caution associated with the unknown. Unfamiliar foods challenge an individual's sense of self and therefore their cultural standing (Fischler 1988). Lupton (1994) argues that variety of food is culturally important and experiencing new foodstuffs is viewed as bettering oneself and as a source of pleasure.

2.22.2 Who we eat with

Eating is a social activity and as such eating habits are "*a product of codes of conduct and the structure of social relationships in which they occur*" (Murcott 1982 p204). A number of studies have demonstrated how food intake is affected when consumed with others. This influence of others on eating behaviour has been termed social facilitation and addresses how and why the behaviour of an individual influences another (Zajonc 1965). The presence of others at meal times has been shown to have a positive influence on the food intake both in free living individuals and in hospitalised patients (de Castro 2002, Edwards & Hartwell 2004).

A series of studies (de Castro & de Castro 1989, de Castro & Brewer 1992, de Castro 1994) examined the factors that increased food consumption in free living individuals. Results from the food diaries of 63 adults indicated that 44% more food was consumed when eating with others compared to meals eaten alone (de Castro & de Castro 1989). Those who live alone tend to consume snacks instead of meals and Seymour (1983) suggested that the reason for this is that eating a meal alone serves

as constant reminder of their exclusion from a social group. This propensity toward consumption in those who live alone was not only observed in the elderly, it also occurred in younger generations. De Castro and de Castro (1989) found that meals eaten alone were lower in calories and contained less fat than meals consumed in a group setting. In addition de Castro and de Castro (1989) reported that meal size was correlated to length of time before initiating another meal when eating alone but not for meals eaten with others, suggesting that the presence of others disrupted postprandial regulation.

Further work found that social facilitation of food intake occurs irrespective of location, timing and type of meals (de Castro 1990) and was not influenced by alcohol consumption (de Castro et al 1990). De Castro and Brewer (1992) reported the influence of group size highlighting that the more people present at the meal the bigger the intake. Meals eaten in large groups were found to be 75% larger than when eaten alone. The effect of group size was not replicated in a study by Clendenen et al (1994) who suggested that a variety of other factors may be responsible for influencing food consumption such as ambiance, conversations or type of relationship.

The impact of relationships on social facilitation was studied by Clendenen et al (1994). Food consumption was compared across three different groups: individuals eating alone; individuals eating with friends and individuals eating with strangers. Findings revealed that individuals eating with friends ate more than those eating with strangers. Similar results were observed by de Castro (1994) who looked at the food intakes from 515 adults. Interactions with family and friends at mealtimes were noted to exert the greatest increase in food intake. De Castro (1994) proposed that 'disinhibition' is an explanatory factor for social facilitation as individuals feel more at ease with friends and family thus facilitating intake. Also mealtimes were observed to be longer when eating with family or friends which facilitated intake.

2.23 Symbolism of food

2.23.1 Food as a gift

Gift giving is a way of expressing love and as "*food is both symbolically and physiologically consumed, it is the ultimate gift, one which nourishes both the body and the psyche" (*Lupton 1996 p46). Lupton (1996) highlights that the symbolic value of the food gift is increased by the level of complexity involved in its preparation.

However Mauss (1990) argues that food gifts are not always freely given and the 'gift relationship is about social reciprocity'. This need for reciprocity can be seen in meals that have been prepared for family with the expectation of praise and affirmation regarding the quality of the meal also demonstrated by eating all the food provided. As the gift of food is an expression of love, if it is not appreciated or particularly if it is refused by the recipient, the giver feels rejected (Lupton 1996).

2.23.2 Food as sign of intimacy

Seymour (1983 p3) highlighted that "*who you eat with defines the social group*" and group membership and the levels of relationship are often disclosed through eating practices (Wood 1995). Work by Douglas (1975) highlighted that a hot meal is usually reserved for close family members and reflects intimacy whereas drinks are usually offered to acquaintances. "*The act of eating together indicates some degree of compatibility or acceptance; food is offered as a gesture of friendship - the more elaborate the fare the greater the degree of implied intimacy or degree of esteem*" (Fieldhouse 1986 p83). When individuals share a meal together the host is sharing part of their self and therefore rejection of the food is perceived as a rejection of friendship (Fieldhouse 1986).

A study by Miller et al (1998) demonstrated that food sharing was associated with close social relationships. In the study 150 college students were shown a video clip of a man and women eating lunch. In the clip five different conditions were shown including the couple sharing food and also feeding each other. The students had to

indicate the nature of the relationship and closeness of relationship on a series of scales. Results showed that sharing food was associated with friendly social relationships and the act of feeding portrayed a closer intimate level of relationship.

2.23.3 Food and emotions

"*Food stirs the emotions, both because of its sensual properties and its social meanings*" (Lupton 1996 p31). The taste and smell of foods can evoke different emotions, either positive or negative. Charles and Kerr (1988) reported that one interviewee in their study described a hatred of the smell of chips as he connected it with those from lower social classes. Murcott (1983) highlighted that a female interviewee expressed the importance of the smell of a home cooked meal for her husband as he arrived home from work as this signified her ability to care for him and for the husband it also provided a sense of familiarity.

Lupton (1996) highlighted that the taste and smell of particular foods can also serve as a reminder of previous experiences connected to the food while recollection of memories related to certain foods can influence food preferences. A food may be avoided because an individual was made to eat it as a child or particular foods may be desired during illness as they are associated with comfort foods from childhood (Lupton 1996).

2.24 Socio-cultural influences on eating in hospital

2.24.1 Social facilitation

Edwards and Hartwell (2004) undertook a study which examined the influence of social facilitation on food consumption in hospitalised patients. Thirteen patients were included in the study and were divided into three groups according to patient preference: group 1 ate round a table, group 2 ate sitting by their bed and group 3 ate sitting in their bed. Food consumption was recorded over a three day period and results showed that group 1 had a significantly higher energy intake compared to the other two groups. Group 1 consumed a larger quantity of macronutrients in their midday meal and carbohydrate intake at this meal was significantly greater compared

to the midday meal consumption of carbohydrate in groups 2 and 3. Although this was a small study the authors concluded that social facilitation appeared to be an important factor in combating poor nutritional intakes in hospital. One of the noted limitations of this study was that patients were not allocated to the groups and therefore those who chose to eat together may have been more social and therefore were already inclined to eat more.

Similar improvement in energy intake when social facilitation was promoted was reported by Wright et al (2006). In this study the food intake of 48 elderly hospitalised patients was collected. Data were only obtained from midday meals with at least three meals being recorded. Thirty patients ate their meals in a ward dining room and eighteen patients acted as controls and ate beside their bed. Results showed a significantly higher energy intake in dining room group with energy intakes 36% greater than those eating beside their bed.

"*Eating together is an expression of nurturing, for some patients having company may be enough to encourage them to eat*" (Jones 2011 p26). Brown and Jones (2009) reported that a 12 month pilot programme using volunteers to assist patients with eating at mealtimes was beneficial for improving patient care. Improvements in nutritional intake were related to the presence of volunteers which helped to address the social aspects of eating (Sneddon and Best 2011).

2.24.2 Cultural determinants on eating

Goffman (1968) described the lack of individual choice and inability to express personal preferences in institutions as the patient's social and cultural identity is stripped away. Patients are "*shaped and coded into an object that can be fed into the administrative machinery of the establishment*" (Goffman 1968 p26). Hospital culture dictates availability and choice of diet with food viewed as a medical treatment (Ferrie 2010). Murcott (1993) highlighted the imposed restrictions on individual food preferences for hospitalised patients contrasted with current society where value is placed on freedom of choice. Restrictions on food choice in hospital

have been deemed partially accountable for the high levels of complaints directed at hospital meal provision (Murcott 1993).

A study by Naithani et al (2008) explored hospital inpatients' experiences of access to food and found socio-cultural influences on eating practices were associated with a reduction in food intake. Over a third of the patients in the study highlighted hospital meal times were inconsistent with their usual eating habits. Eight out of the forty eight patients struggled to eat the evening meal as it was served much earlier than was customary and as a result these patients reported feeling hungry in the evening. Meals also failed to meet cultural preferences as over half the ethnic minority patients reported that the food was not cooked to their personal taste nor smelled appetising (Naithani et al 2008).

2.24.3 Meaning of food

Literature relating to the meaning of food has predominately focused on food intake and eating behaviour in free-living individuals (Hetherington 2002). Other studies have explored the meaning of food in disease such as patients with heart failure (Jacobsson et al 2004), breast cancer (Adams & Glaville 2005) and carers of patients with terminal cancer (Poole & Froggatt 2002). The common finding across the studies was that patients' experience of food changed over the course of the disease. Food was socially symbolic with positive feelings of community and social interaction or negative feelings of deprivation attributed to missing eating and the associated social environment.

McQuestion et al (2011) examined the changed meaning of food associated with radiation treatment for head and neck cancer. The findings from the qualitative interviews with 17 patients revealed that food took on new meanings and was associated with loss in three areas of their lives: physical, emotional and social. Physical losses were related to the problems with eating as a result of treatment such as pain, swallowing difficulties, taste changes, dry mouth and loss of appetite. Emotional losses were related to the loss of enjoyment and pleasure of eating and social losses were associated with the difficulties eating with others. McQuestion et

al (2011) highlighted the importance of an awareness of these issues in order to adequately support patients and provide ways of managing these difficulties. "*Food is never just 'food' and its significance can never be purely nutritional. Furthermore, it is intimately bound up with social relations, including those of power, of inclusion and exclusion, as well as cultural ideas about classification (including food and non-food, the edible and the inedible), the human body and the meaning of health*" (Caplan 1997 p3).

2.25 Socio-cultural influences on eating after critical illness

A search of the literature revealed that there was no work in relation to socio-cultural influences on eating after critical illness. It is speculated from the literature in free-living and hospital populations that socio-cultural factors may have an influence on food intake in post ICU patients.

2.26 Summary of section 3

The literature relating to the socio-cultural aspects of eating provides an understanding of the factors that influence what people eat, who they eat with and the symbolic meanings attached to food. Socio-cultural influences have been demonstrated to affect eating in hospital patients and as such partially account for variations in nutrition intake in this patient group. There is a need for work to be done in patients after critical illness to determine the impact of socio-cultural influences in this patient population and examine if and how these factors interlink with other identified issues that influence nutritional intake.

Section 4

2.27 Overview of section

In recognition of the need to study patients' experiences of eating from a broad perspective this section explores a recent review by Larsen and Uhrenfeldt (2013)

that examined patients' experiences of reduced food intake from both a biomedical and social sciences perspective.

2.28 Introduction

Larsen and Uhrenfeldt (2013) highlighted the need for an innovative approach to nutrition and stated that "*hospital patients' need for nutrition is well described as regards energy and protein intake based on biomedical evidence. However, in spite of the increased knowledge in this area, patients do not automatically raise their consumption to the level needed during hospitalisation. On the contrary, people have their reasons, tastes and traditions. Therefore knowledge of patients' personal experiences and reasons for not eating or drinking sufficiently, their individual feelings, preferences and rejections might provide professionals with insight into the complexity of eating and drinking disorders, and the potential subsequent malnutrition and how to help patients deal with their nutritional challenges during illness*" (p185).

Larsen and Uhrenfeldt (2013) examined 13 articles with the aim of identifying patients' lived experiences of having a reduced intake of food and drink during illness through a literature review. Studies were included if they were based on qualitative data, examined nutrition during illness with an emphasis on lived experiences. Eleven of the thirteen studies were carried out in Scandinavian countries; the remaining two were conducted in England. The fact that the majority of the studies were from Scandinavian countries could have influenced the findings as they may operate different food service systems and ward staff numbers. There were no limits placed on the year of publication for the articles; the oldest study was published 15 years ago. Nutritional practices have evolved over the last 15 years and it is questioned whether it is comparable with current practice. All of the studies used interviews to collect the data, some also used observations. Methodologies differed between the studies with some adopting a phenomenological approach, grounded theory or an ethnographic approach.

The findings revealed three themes: serving of food and drink, modifications related to illness and nutritional care as provided by health professionals. In the first theme, patients highlighted issues with flavour, temperature and texture of food, and the influence these had on intake. Other identified issues were related to the eating environment with some patients expressing a preference to eating alone, others wanting to eat with others. Patients also experienced interruptions at mealtimes, problems with missing meals due to investigations and issues with timing of meals. Under the second theme patients' experienced physical changes that affected their intake of food including poor appetite, nausea, vomiting, fatigue and changes to smell. Psychological problems that influenced nutritional intake were fear, shame, reduced body control, embarrassment, loss of hope, loneliness and inability to interact in social activities. The third theme highlighted patients' experiences relating to the influence of healthcare professionals in nutritional care.

The review highlighted that patients found they did not get assistance with eating, nor the necessary advice and information about their nutritional needs. The authors concluded that there was a need to "*refocus on caring as an essential part of nursing practice*" (Larsen & Uhrenfeldt 2013 p192) and recommended a number of changes to current nutritional practice including the need to provide appropriate nutritional information and advice, creation of social eating environments and consideration of individual preferences.

2.29 Summary of chapter

The literature has demonstrated that there is a multitude of factors that can influence nutritional intake. Typically, healthcare related studies have looked at the organisational and physiological factors affecting intake while the sociological literature addressed the psychological and socio-cultural influences on eating. This literature review identified numerous organisational issues influencing nutritional care in a general patient population and also explored the impact of socio-cultural influences on eating. Additionally, the review highlighted the sociological evidence demonstrating the impact of illness on the body, self and identity. However, no work has looked specifically at patients' experiences of nutrition after critical illness in

order to explore the factors that influence nutritional intake and examine how they interact. The aim of this doctoral thesis was therefore to provide a comprehensive understanding of the factors influencing nutritional recovery, and the relationship between them, in patients after critical illness.

The next chapter will describe an exploratory study that was carried out in order to investigate the topic area and at the same time clarify the research approach and method.

Chapter 3: Exploratory Study

3.1 Overview of chapter

This chapter describes an exploratory study that was carried out as the first phase of this research. It will begin by explaining the rationale for the exploratory work prior to the main study and the initial research questions that were addressed. The methods used in the study will be described and then the researcher will outline the ways in which the analysis of the data was undertaken. The latter part of this chapter will report the findings from the study. Lastly the researcher will describe how this exploratory study contributed to her understanding of the research process and the changes that were made to the research design of the main study in light of this exploratory work.

3.2 Rationale for Exploratory Study

In order to maximise the methodological quality of the main study the researcher opted to undertake an exploratory study of 10 patients during their ward stay. The purpose of this exploratory work was: to determine the most appropriate methodology for the main study; ascertain the timing of the interviews and observations and refine the interview questions and observational schedule.

3.3 Research questions

The research questions addressed in this exploratory study were:

- What are the factors that influence nutritional intake in patients after intensive care?
- How do ward staff perceive the factors that impact on ICU survivors' nutritional intake?
- How should future work be designed to explore the relative importance and inter-relations of the identified factors that influenced intake?

3.4 Methodology

The researcher opted to use a case study approach for the exploratory study after considering the questions proposed by Yin (1994). The first question ascertains if the research question describes the incidence of a phenomenon or tries to explain a phenomenon. The second question examines if the research requires control over behaviour or does it describe naturally occurring events. The final question asks if the phenomenon is contemporary or historical. As this study was exploratory in nature, aimed to describe naturally occurring events, and the phenomenon was contemporary, the researcher chose to use a case study approach.

3.4.1 Case study approach - definition and rationale

There are prolific definitions in the literature of a case study, however, arguably the most comprehensive definition was provided by Yin (1994). Yin (1994) defines a case study as "*an empirical enquiry that investigates a contemporary phenomenon within its real-life context*" (p13). The 'phenomenon' in this case was the process of nutritional recovery. Lewis (2003) argues that case studies should be used when "*no single perspective can provide a full account or explanation of the research issue, and where understanding needs to be holistic, comprehensive and contextualised*" (p52). The researcher's background work (Chapter 1) had highlighted the complexity of some of the issues influencing nutritional care and the need for a detailed understanding of these and further exploration of the process of nutritional recovery in patients after critical illness.

3.5 Data collection methods

Interviews and observation were the data collection methods used in the exploratory study. These were also employed in the main study and a detailed explanation of the two methods is provided in chapter 4. In order to provide some context for the reader a summary of these methods is provided below.

3.5.1 Overview of Methods

- Patient interviews were carried out on discharge from ICU and weekly thereafter for the duration of their hospital stay.
- Patients were observed on the ward and information about the management of their rehabilitation and process of recovery was also collected from medical and nursing notes.
- Ward based staff interviews were carried out where possible.

3.5.2 Interviews

Interviews were the main method used in the exploratory study and these were conducted by the researcher when the patient was discharged from ICU and weekly for the duration of their ward stay. Interviews with ward staff were also carried out. The researcher used note taking to collect the data from the interviews.

3.5.3 Observation

In the study the goal of the observation process was to examine ward culture and how this may impact on nutritional recovery. Initially the researcher went up to the ward on a daily basis to record observations however quickly realised, as more patients were recruited into the study, that such frequent visits were not going to be possible. For practical purposes observations were carried out three times a week.

Observations were recorded in a management log which contained an observational schedule to allow the recording of certain aspects of recorded behaviour. It included a checkbox format to record various aspects of service delivery including the delivery and consumption of meals, nutritional supplements and snacks.

3.6 Setting and sample

3.6.1 Location

The setting for the study was a large teaching hospital in central Scotland. The 18 bedded ICU, where patients were recruited from, is classed as a general ICU which

means that the population comprised of a mix of medical and surgical patients (including trauma and obstetrics), but not cardiac or neurosurgery. This location was chosen due to the size of the unit which would ensure sufficient numbers for the study. It is also where the researcher is currently employed so access and recruitment of patients on discharge from ICU would be aided.

3.6.2 Access

The researcher is currently employed as a clinical dietitian working in ICU therefore access to this patient group was relatively straightforward. Permission to undertake the study had been granted by the Critical Care Clinical Director. As an NHS employee the researcher had access to the local critical care database which holds individualised patient information. Permission to use this clinical information to identify potential patients for the study was granted by the Professional Lead for ICU.

3.7 Eligibility criteria

3.7 1 Inclusion:

- Patients who had received ≥48 hours of mechanical ventilation in the ICU and were ready for discharge to a ward.

3.7.2 Exclusion:

- Patients who would be discharged into pre-existing rehabilitation programmes e.g. stroke or liver transplant.

The inclusion criteria of ≥48 hours of mechanical ventilation was chosen as this population comprises 50% of all mechanically ventilated ICU admissions hence would ensure adequate numbers. Patients who were going to be discharged into pre-existing rehabilitation programmes were excluded as this was likely to have a positive influence on nutritional care. Local data shows that these patients comprise less than 10% of the current case mix.

3.8 Time Frame

Local data showed there would be 200 eligible patients annually. Assuming a pessimistic 30% recruitment rate (recent studies in the ICU had achieved a 50-70% recruitment rate) it was expected that 4-5 patients would be enrolled per month. It was therefore anticipated that the study would take 3 months to complete.

3.9 Sample

The current ICU case mix consists of 42% surgical patients, 48% medical patients, 8% liver transplant patients and 2% from obstetrics and gynaecology (local data). It was therefore envisaged that around half the patients recruited would be discharged from ICU to a medical ward, the other half to a surgical ward. The mean age of patients admitted into ICU in 2006/2007 was 55.6 years with equal numbers of males and females (local data). Hence it was likely that a similar proportion of males and females would be recruited, potentially including a higher percentage of older patients. As this was an exploratory study the plan was to recruit 10 patients on discharge from the ICU.

In this exploratory work judgemental or purposive sampling was employed to ensure the selection of a range of patients including different genders, ages and ward destinations. The researcher wanted to ensure that a broad range of patients were included in the study as her background work had suggested that nutritional care may vary across ward speciality and it is also widely recognised that elderly patients have a high incidence of nutritional problems (Wells & Dumbrell 2006). Patton (1990 p169) highlights that "*the logic and power of purposeful sampling lies in selecting information-rich cases for study in depth*". Moore (2010) demonstrated that a researchers' prior knowledge about the population and problem can be utilised to select cases to be included in the study. This researcher argues that her dietetic training and years of experience working with an ICU patient population was beneficial in the initial selection of patients.

3.10 Ethical approval

Ethical approval was sought from the Scotland A Research Ethics Committee. Approval was necessary from this research ethics committee as patients who are unable to give their consent were included in the research. In these cases consent was sought from the patient's nearest relative or welfare guardian. When the patient became competent to give consent, their informed consent was obtained. To ensure that patients were informed about the proposed research, the researcher explained and discussed the implications of the study and distributed an information leaflet. The patient was then given time to think about the study and encouraged to speak to other family members. Dale (2006) recommends this approach as it enhances research quality by ensuring transparency of purpose and methods.

3.11 Findings

3.11.1 Methodological findings

This section describes the methodological findings from the exploratory study. Firstly it highlights the limitations of the case study approach and then identifies the need to modify the data collection methods.

3.11.1.1 Limitations of case study approach

The researcher's original intention was to use the case study approach previously described in this chapter to provide in-depth data from 10 patients. However, during the early stages of data collection the researcher became increasingly aware of the methodological limitations of the case study approach which are elaborated below.

The purpose of a case study is to describe a contemporary phenomenon within its real life context (Yin 2003). A description simply answers the question "what is going on here?", whereas discovery answers the question "what is going on and how?" (Becker 1993b). The researcher realised that in order to fully address the research aims, the methodology would need to provide an understanding of the social processes in order to discover what was going on. For example a description of nurses' perceptions of post ICU patients identified these patients as demanding and

needy with nurses being wary of doing too much for them. However, it was discovered that these perceptions stemmed from a lack of understanding of the complex needs of a post ICU patient and resulted in negative stereotyping.

Another limitation of the case study approach is that analysis of the findings is one of the least developed aspects of this methodology (Yin 1994) and the researcher was concerned that this could have allowed ambiguous evidence to influence the findings thus threatening the reliability and validity of the study.

After recruiting two patients into the study using the case study methodology, the researcher realised that she needed to go beyond what a case study was able to do in order to address the purpose of her research. The researcher opted to adapt her research design to use a constructivist grounded theory approach for the remainder of the exploratory study. Using a grounded theory approach would allow the construction of theories that explain a phenomenon and represent another's views (Wimpenny & Gass 2000). It also provides "*flexible guidelines for collecting and analysing qualitative data in order to construct theories 'grounded' in the data themselves*" (Charmaz 2006 p2).

3.11.1.2 The need for modification of methods

3.11.1.2.1 Timing of interviews

By undertaking the qualitative interviews on the ward the researcher found that there were distinct stages in the recovery process and this influenced the patients' responses to the interview questions. The initial period on the ward was when the patient appeared to be the least interested in eating as they were adjusting to a different environment and trying to come to terms with all that had happened to them. The first week on the ward was often when patients reported experiencing physiological and psychological issues that influenced their eating. During subsequent weeks patients then highlighted a range of organisational issues that impacted on their nutritional care. Conducting interviews at a variety of time points enabled the researcher to capture a wider range of experiences that influenced nutritional recovery.

The researcher also found that the time of day influenced the patient's ability to participate in an interview. Patients were often still asleep first thing in the morning and were tired in the afternoon and less able to answer questions. Through visiting the patients at different times during the day the researcher found that the best time of day to conduct the interviews was late morning.

3.11.1.2.2 Interview schedule

It quickly became clear to the researcher that the interviews would need to be short out of necessity as this patient group tired easily and found it difficult to concentrate for long periods of time, particularly during the initial period on the ward. The need for short interviews came from the researcher's experiences of having a patient dozing off during the interview, another repeatedly asked to be reminded of the question and a number of patients who actually said they were too tired to continue the interview.

The researcher had planned to adopt an unstructured approach to interviews, however the researcher realised during the early stages of the study that post ICU patients, especially during their first few days on the ward, struggled to formulate answers to broad open ended questions. An excerpt from the researcher's fieldnotes demonstrates this.

JM: I'd like to talk about your experiences eating after intensive care. How do you feel about food at the minute?

Patient 4: Emm, emm I'm not sure, emm I cannae think, err what wis the question?

Reflective memo: this patient had a long ICU stay, had been transferred to the ward three days ago. He looks exhausted, frail and thin with obvious muscle wasting. I am not convinced that this patient has the mental capacity at the minute to answer 'abstract' questions and I may have to provide more structure to my questions.

The researcher was aware that the aftermath of critical illness can impact on cognitive function resulting in impaired memory, attention and concentration (Jackson et al 2009). After two or three attempts at using the broad open ended questions in the exploratory study the researcher changed her approach to use more

direct questions based on the sensitising concepts from previous background work and the literature review. As the patients' clinical condition and cognitive function improved over time the researcher was able to ask more detailed questions.

The researcher found that patients were very keen to talk about their experiences relating to nutrition. She initially focused specifically on issues relating to eating, however it soon became apparent that there were many broader multidimensional processes influencing nutritional intake that needed to be addressed.

The researcher used note taking to gather the information from the interviews however was concerned that this approach made her appear distracted during the interview and she also questioned the accuracy of note taking.

3.11.1.2.3 Staff interviews

Interviews with ward staff were also part of the original research design and questions included 'From your perspective, how do you think patients eat after ICU' and "Is there anything you think influence patients nutritional intake when they are on the ward". The researcher attempted to approach staff who were caring for the patient in the study. However, pressure on staff time meant that interviews were very brief and often interrupted by the need to attend to clinical duties such as patients buzzing for attention, phones ringing, being asked to help by another nurse or a doctor interrupting to pass on information. This highlighted the busy, stressful nature of the ward environment and these situations were recorded by the researcher as part of her observational data.

3.11.1.2.4 Observation

In the exploratory study the researcher had a more unstructured approach to the recording of observations to provide an overview of the ward setting with particular detail on mealtimes, an area that was highlighted from previous work. Initial analysis of the exploratory data revealed interactions between ward staff and patients, mealtime practices and variations in accounts of patient’s nutritional intake

from medical staff, nursing staff and dietitians were recurring patterns in the data. The need to observe mealtimes in particular was demonstrated in the exploratory study as an excerpt from the researcher's fieldnotes highlights:

Tuesday March 6th 11.50
The smell of food pervades the ward. Lunch is about to be served. The nurse goes into the patient's room which has been in darkness for most of the morning. The patient is asleep as he has been awake most of the night, he looks exhausted, pale and unkempt. The nurse calls for a clinical support worker to help her to position the patient ready for lunch. He is propped up into a sitting position with pillows and his lunch tray is brought to him. Three courses all at once, the lids are taken off and the food is chopped as the patient is physically too weak to do it himself. The nurse is then called away and the patient sits there looking at the food, unable to feed himself.

JM reflection: Smell of food throughout the ward, not a great smell. Lunch is served really early. Food served all at once, little communication with patient, clinical detachment from nurse, impression of body in bed not person. Nurse looks busy, harassed, nutrition not a priority? – need to follow up in interview, how did patient feel?

3.11.1.2.5 Recording observations

Observations were initially recorded in a management log which contained an observational schedule to allow the recording of certain aspects of observed behaviour. It included a checkbox format to record various aspects of service delivery including the delivery and consumption of meals, whether any necessary assistance was provided at mealtimes, delivery and consumption of nutritional supplements and snacks. This provided a structured approach to observation and the researcher found that this approach was successful in recording the frequency of the organisational issues that influenced nutritional intake. However, the format of the logs meant that the context surrounding the organisational issues was not captured and when the researcher started to analyse the data she found that the lack of context limited her understanding of the full extent of the problem.

3.11.2 Preliminary findings from data

Data analysis using a grounded theory approach is a cyclical process that starts with coding of the data. Chapter 4 provides a detailed account of grounded theory

analysis employed in the study, however in order to provide clarity in this chapter a summary of the analytic process is provided. In grounded theory analysis the starting point is a basic description, then conceptual ordering and lastly to theorising (Patton 2002). The first stage of the process of analysis in this study involved action coding, involving a line by line analysis of the data from the interviews was undertaken as described by Charmaz (2006). Incident to incident coding was then conducted for the observational data. The process of constant comparison was then utilised to establish analytic distinctions (Glaser and Strauss 1967). From this, focused coding was used to synthesize the data and theoretical categories were developed. Theoretical memos played an integral part in the analysis process, promoting researcher reflexivity and transparency in the research process (Charmaz 2006).

As previously highlighted the sample size of the study was small and the preliminary analysis allowed some concepts to be populated, although theoretical saturation was not achieved. The process of analysis will be described alongside the emerging preliminary findings from the study.

3.11.2.1 Patient characteristics

Over the three month recruitment period (12th April to 5th July 2010) 10 patients were approached for inclusion in the study. Two patients declined to give consent and so the sample consisted of 8 patients, 5 males and 3 females. The patients ranged in age between 29 to 74 years with a median age of 55 years. The median length of ventilation days was 19.5. Five patients were transferred from ICU to a surgical ward, the remaining 3 to a medical ward in the hospital. Table 9 summarises the demographic details of the patients.

Table 9: Demographic details of patients

n=8	Median (IQR)	Min Max
Age (years)	55 (38-73.5)	29 74
Apache II*	19.5 (16.5-25.5)	13 29
Length of ventilation (days)	19.5 (7.5-31)	4 57
Length of ward stay (days)	29 (12-37.5)	2 64

*Apache II (Acute Physiology and Chronic Health Evaluation II) is a severity-of-disease classification system used in ICU (Knaus et al 1985). A score from 0 to 71 is calculated based on several measurements; higher scores correspond to more severe disease and a higher risk of death.

3.11.2.2 Physiological issues influencing nutritional intake

Open coding of the data highlighted that all patients were experiencing a number of physiological changes. These are illustrated below:

"*I'm not used to eating now. Everything tastes yucky, a metallic taste.*" (008)

"*I can't hold a fork to get food in my mouth. I'm too tired to eat and eating tires me out.*" (004)

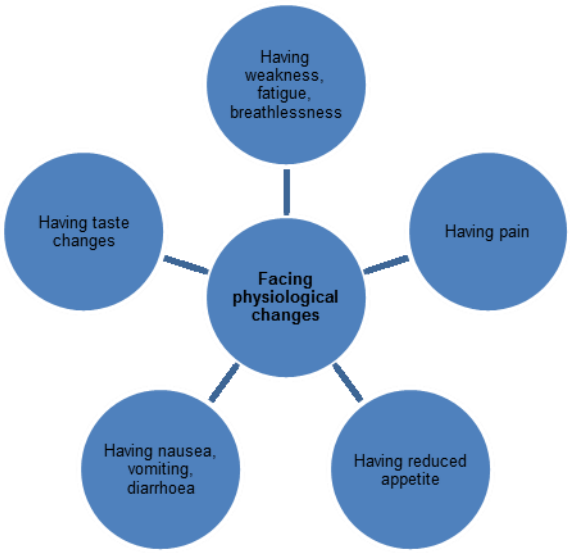
"*I've gone off a lot of foods I liked. I've got no appetite. My feeding tube came out this morning but the doctor says I've to try and eat.*" (006)

"The idea of lifting a spoon is too much hard work." (005)

"*I feel full really quickly. I have a few spoonfuls then it's enough.*" (003)

These were coded as 'having reduced appetite', 'having early satiety' and 'having taste changes'. During the process of focused coding these open codes were conceptualised under the focused code of 'facing physiological changes' (figure 6).

Figure 6: Focused code 'Facing physiological changes'



Literature has highlighted that poor appetite, early satiety and taste changes are associated with critical illness (Griffiths 2002). Loss of appetite was the most common problem reported during the first few days on the ward The other physiological changes that were deterrents to eating included changes to the taste and smell of food and drinks, with some likening it to a strange metallic taste and also feeling full after eating only a few mouthfuls of meals.

Other physiological problems reported by patients were nausea, vomiting and diarrhoea. These gastrointestinal symptoms were primarily experienced by the three patients on the surgical wards. Patients attributed different reasons for these symptoms; some felt that it was a result of their underlying disease, others blamed the enteral nutrition, while others ascribed their symptoms to the fact that they had not eaten normally for some time. However, despite the variation in rationale, patients all reported that their symptoms had led to reductions in their oral intake.

Another physiological factor that was attributed to influencing nutritional intake was the profound weakness and fatigue experienced by all patients. One patient said "*I'm so tired. I'm not doing anything but I'm exhausted. I'm too tired to eat and eating tires me out*". Another patient stressed "*The idea of lifting a spoon is too much hard work*".

Pain was another issue frequently highlighted. Some complained of generalised joint pain with one patient describing himself as "*....like the tin man. I need a can of oil*". Other patients suffered from localised pain, usually abdominal in origin. For some the pain became all-consuming and it was noted that these patients had a tendency to disengage from the rehabilitation process and refuse treatment. Concurrently, nutritional intake decreased during this time. It was also observed that the treatment of pain could itself affect nutritional intake. Reported side effects of the pain medication included constipation and drowsiness. One patient commented that "*They are pumping me full of drugs. The strong medication is making me really sleepy. I fell asleep on the commode yesterday afternoon*".

3.11.2.3 Psychological struggles influencing nutritional intake

Open coding also highlighted a number of psychological issues experienced by patients that ranged from negative feelings to low mood and depression. The quotes below illustrate this:

"*Come to think of it I do eat more when I am relaxed. My diet is affected by stress.*" (004)

"*My mood is really low. It's depressing being here.... I'm at a low stage at the minute. Food is the last thing on my mind.*" (008)

"*I'm lying here doing nothing. I feel hopeless. I feel like I can't do it (eat).*" (006)

"*I'm really low. I'm assuming I'm a bit depressed. I just get rid of one thing and something else starts.*" (003)

These were coded as 'experiencing negative emotions', 'having low mood' and 'having depression'. During the process of focused coding these open codes were conceptualised under the focused code of 'facing psychological struggles' (figure 7).

Figure 7: Focused code 'Facing psychological struggles'

Negative emotions such as fear, worry, anger and low mood were consistently reported problems and these correlated with other challenges that patients were facing. Patients expressed their difficulties in dealing with the huge change from ICU to the ward, the trauma of their ICU experience, frustrations with perceived lack of communication, challenges of dealing with exhaustion and a desire to get home tempered by an increasing realisation of their level of debilitation.

3.11.2.4 Emerging category related to bodily experience

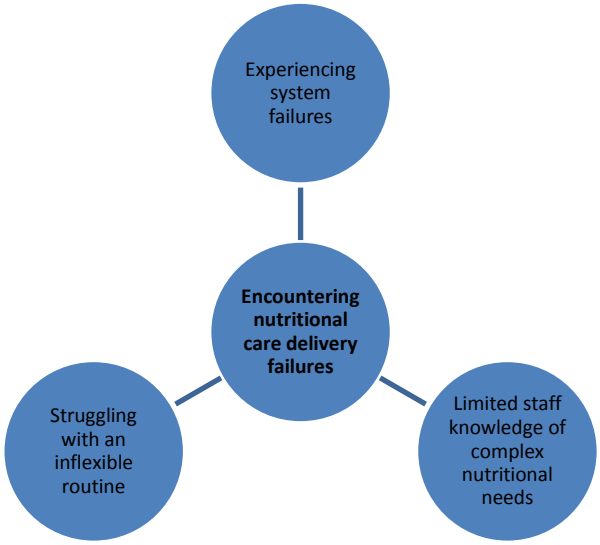
Through the process of constant comparison the researcher realised that 'facing physiological changes' and 'facing psychological struggles' were properties of an emerging category that was related to the way that patients experienced their body after critical illness. This connection was made through the process of memo writing where the researcher started to question if there was a link between bodily changes, the way patients saw themselves, and how others saw them.

3.11.2.5 Organisational issues influencing nutritional intake

Open coding identified a number of organisational issues that impacted on the patients' experience of nutritional care. Figure 8 details the emerging category 'encountering nutritional care delivery failures' and the properties associated with this

category: struggling with an inflexible hospital routine', 'experiencing system failures' and 'limited staff knowledge of complex nutritional needs'.

Figure 8: Emerging category 'Encountering nutritional care delivery failures'



3.11.2.5.1 Struggling with an inflexible hospital routine

One of the recurring patterns in the data related to patients experiences of meal times. Patients struggled with the quantity and quality of the food as the quotes below illustrate:

"*I'm not enjoying eating. Hospital food is not like your mammy cooks.*" (002)

"*I'm going to struggle just to eat soup and bread. I find the quantity off putting.*" (005)

"*The stuff in here is inedible. My wife is bringing in all my food.*" (003)

"*It's horrible. I wouldn't give it to my dog."* (006)

This links with the physiological changes the patients were experiencing as lack of appetite, taste changes and early satiety can affect the amount of food that is consumed at mealtimes. Current hospital routine dictates that meals are served three times a day. This structured routine limits the nutritional intake of patients

experiencing physiological changes due to reductions in food quantity at mealtimes combined with a lack of additional snacks to supplement intake.

3.11.2.5.2 Experiencing system failures

Patients also experienced a number of service delivery failures which affected their nutritional care such as missing meals because they were fasting for a procedure or away from the ward for an investigation over meal times. One patient commented "*I was away for a scan and when I got back lunch was over and nothing had been left for me*" (008). Another patient missed a meal because nothing had been ordered for him. Observations at mealtimes also revealed a number of patients who were unable to eat themselves as they were too debilitated and meals were simply cleared away uneaten at the end of the meal time.

Problems were identified in the delivery and consumption of nutritional supplements. Supplements were signed as being given to the patient on the drug kardex and yet, on questioning, the patient denied receiving them. Delays in dietetic review meant that in some instances supplements were being offered to the patient but were being refused because they were disliked. Additionally although the supplement may have been given to the patient, it was clear that they were not always consumed as unopened or partly drunk bottles were observed on patients' tables. Delivery issues were also noted with snacks with one patient commenting "*I haven't had any* (talking about the yoghurts and crackers and cheese)*, I didn't realise I had to ask for them*. *The dietitian says there will be a huge supply in the pantry for me.*" (004)

Other service delivery failures included problems with the delivery of enteral nutrition. Six patients were transferred to the ward on enteral nutrition, two of these were being fed through jejunostomy tubes, the other four had nasogastric (ng) tubes insitu. Patients rarely received their prescribed volume of enteral feed. Observations from the fluid balance charts revealed that there were delays starting feeds, feeds were stopped due to tube dislodgement, fasting for a procedure or administration of medication that interacted with the feed. Again, delays in dietetic review meant that these problems were not identified or resolved promptly, resulting in reduced

nutrient delivery. One patient highlighted that "*My feed is not stopped and started again at the same time each day. My weight has dropped again. Do you think I'm getting enough*?" (001).

3.11.2.5.3 Limited staff knowledge of complex nutritional needs

Observations highlighted that post ICU patients were perceived as needy and demanding by ward based nursing staff. During observations on the ward the researcher overheard a conversation between two nursing staff describing a post ICU patient as "*precious*" and warning her colleague against "*doing too much*" in relation to the provision of care. This information was not evident from the two brief interviews that were held with junior nursing staff. During the interviews concerns were raised about the general busyness of the ward however no specific issues were highlighted relating to post ICU patients. This was given the code 'limited understanding of complex nutritional needs from nursing staff' however the researcher recognised that more data was necessary to refine this concept.

3.12 Conclusion from exploratory study

The findings from this exploratory study support previously published research that highlighted the range of problems experienced by patients after ICU (Chapter 1). This exploratory study focused on the nutritional issues and produced valuable findings which indicate that patients' experiences of eating are influenced by their physiological and psychological state and a number of nutritional care delivery failures.

Additionally the exploratory study revealed a number of research design issues and provided the researcher with valuable insights into the challenges associated with research in this patient population. Revisions to the research process were made over the course of the exploratory study and subsequently led to revisions in the research design of the main study. The issues and insights highlighted from the exploratory study are discussed in the next section.

3.13 Discussion

3.13.1 Alterations to research design of main study

3.13.1.1 Research questions

The research questions for the exploratory study focused on identifying the factors that influenced nutritional recovery in hospital from a patient and ward perspective. Through undertaking the exploratory study the researcher realised that these questions were too simplistic and needed to encapsulate patients' experiences of eating in order to gain a fuller understanding of the process of nutritional recovery.

The researcher also realised that her background as a clinical dietitian had meant that her initial focus had been on nutritional intake. The dietetic world view follows a quantitative paradigm which is associated with positivist assumptions and finding the objective truth (Schrag 1992). The findings from this exploratory study challenged the traditional dietetic construct of providing nutritional support to improve nutritional intake and simply measuring nutritional intake as an indication of an effective intervention. It was clear that this approach is naive in such a complex patient group. The researcher realised that the main study needed a broader scope in order to capture the multidimensional aspects of food and eating. This allowed the formation of new research questions (Chapter 4).

3.13.1.2 Methodological approach

As previously highlighted the researcher realised the limitations of the case study approach for her research during the initial stages of data collection and opted to use grounded theory methodology. The researcher found that using grounded theory provided a set of principles that enabled her to view the familiar with fresh eyes (Charmaz 2006). The grounded theory approach is complex and is 'learned by doing' (Schreiber 2001) hence the exploratory study provided the researcher with the opportunity to carry out some of the main principles in grounded theory, namely the early analysis of data and the process of constant comparison.

In addition the researcher realised that the qualitative component of the study was crucial to understanding the process of nutritional recovery and a qualitative approach should inform the overall approach to the research.

3.13.1.3 Methods

3.13.1.3.1 Interviews

The interview method is highly reliant on the interviewee's ability to express, interact, formulate and recall their understandings (Mason 2002) yet post ICU patients commonly suffer from reduced cognitive function resulting in impaired memory, attention and concentration (Jackson et al 2009). In order to facilitate the interview process the researcher changed her approach to use more direct questions based on the sensitising concepts from previous background work and the literature review (Appendix 3). The semi-structured interviews were kept to approximately 15-20 minutes in length, to prevent them from becoming onerous for patients.

The researcher observed that different issues influenced nutrition at various time points during the patients' hospital journey as they faced and dealt with new challenges. The patients' condition was also observed to change quickly in terms of resolving symptoms and issues thus highlighting the importance of capturing this process. These observations led the researcher to revise the interview schedule. Different questions were asked at the identified time points: on discharge from ICU and then weekly for the duration of their ward stay. The questions on discharge from ICU included 'What was your eating like before you were in intensive care?', 'What's eating like for you at the minute?', 'How have you been feeling about what has happened to you?', 'Do you think it influences how much you eat?' Weekly questions included 'How has your eating been this week?', 'What's the main issue been for you this week?', 'Is there anything that has made eating more difficult for you this week?' This approach served to elicit interesting and informative data from the interviews.

The exploratory study also highlighted the challenges of interviewing staff in a busy ward environment. This in itself was an observation of the demanding workload

experienced by ward staff. Through undertaking the exploratory study the researcher realised that observation of ward practice and staff interactions provided more information than the short, disjointed interviews with staff. In the main study the researcher opted not to interview staff.

The researcher had opted to take written notes during the interviews in the exploratory study during the interview however she was concerned about the accuracy of this approach. In the main study the researcher audio recorded all the interviews to increase accuracy and therefore overall study rigour.

3.13.1.3.2 Observation

On-going analysis of the data revealed that interactions between ward staff and patients, mealtime practices and variations in accounts of patient's nutritional intake from medical staff, nursing staff and dietitians were recurring patterns in the data. In the main study observations took a more focused approach around these highlighted areas.

The process of recording observations also changed over the course of the exploratory study. The management logs were changed to weekly case report forms (CRFs) to provide a more qualitative based tool to capture observations about the patient's nutritional care (Appendix 4). These CRFs incorporated all the research tools used to gather information on a weekly basis. The CRFs prompted the researcher to document any organisational issues from the medical notes, nursing notes, drug kardex or observations of ward practice by providing a list of previously identified issues such as service delivery failures or problems relating to meal service. The field note page of the CRF was divided into two columns. The left hand column detailed the content of the observation. The researcher's insights and reflections relating to specific parts of the observation were documented in the right hand column. The researcher wrote short hand notes during observations and then wrote a more detailed account after leaving the ward.

The revised research tool was piloted on the last two patients in the exploratory study and the revised format allowed freehand detailing of notes which included descriptions of context and timing of issues. Although the information gathered was more laborious to analyse, it enabled the researcher to start to develop links between organisational issues and the other emerging concepts such as the inter-relation of meal service structure on patients facing physiological changes.

3.13.2 Emerging themes from analysis of data from exploratory study

The exploratory study provided valuable insight into patients' experiences of nutrition after critical illness and the use of grounded theory methodology provided the researcher with "*systematic, yet flexible guidelines for collecting and analysing qualitative data in order to construct theories 'grounded' in the data themselves*" (Charmaz 2006 p2). The emerging themes from the data were around patients' experiences of their body and the influence of the organisation of nutritional care. These themes were not fully saturated and the main study therefore focused on collecting data to add to and saturate the categories relating to patients experiences of their body after critical illness and nutritional care delivery issues. In addition the researcher became increasingly aware of a number of socio-cultural influences on eating and planned to gather more data in the main study in order to define this category and its properties.

3.14 Summary of chapter

The aim of this chapter was to describe the exploratory study that was carried out as part of the research. Its purpose was not to offer a full description and explanation for the methods chosen but to inform the reader of why and how the research design was amended during the course of the study in light of the researcher's experiences. Changes to the research questions, methodology and methods, particularly the refining of the interview and observation process are described. The preliminary analysis and emerging themes from the exploratory study are also highlighted.

The next chapter will address the research design of the main study that was shaped by the findings from the exploratory work.

Chapter 4: Research Design of the Main Study

4.1 Overview of Chapter

The purpose of this chapter is to give a detailed account of the research design of the main study and describe the researcher's journey through this process. Firstly, it will explore the methodological considerations in mixed methods research design and provide a defence for the use of a qualitative paradigm. The theoretical and methodological approaches in relation to grounded theory will then be addressed. The methods chosen, the process of data collection, study setting and sample and the ethical considerations are described. It also includes a reflection on the research process and the issues the researcher faced during this time. Finally, the data analysis procedures used in the study are outlined.

The reader will note multiple references to Crotty (1998) throughout this chapter. The content for his book 'The Foundations of Social Research' was directed by the needs of his students, and this researcher found that his step by step approach to the research process was helpful and informative. The researcher adopted Crotty's framework to guide her own research approach.

4.2 Research aims

The research aims of this study were to:

- Provide a comprehensive understanding of the factors influencing nutritional recovery, and the relationship between them, in patients after critical illness.
- Develop a model of care that will improve current management of nutrition for patients recovering from critical illness.

4.3 Research questions

The following research questions were formulated to explore patients' nutritional recovery after critical illness:

- How do patients experience eating after critical illness?

- How do organisational, psychosocial and physiological factors affect nutritional recovery?
- How do organisational, psychosocial and physiological factors interact to affect nutritional recovery?

These questions evolved in light of the exploratory work that was carried out by the researcher. The preliminary findings from the exploratory study alluded to the complexities of eating for patients after critical illness and indicated that nutritional intake was influenced by many factors. These revised research questions seek to explore the process of nutritional recovery in patients after critical illness.

4.4 Mixed Methods Research

The researcher has used a mixed method research design which can include both quantitative and qualitative methods and as such incorporates the two differing paradigms discussed widely in the literature: the quantitative and qualitative paradigms (Phillips 1987). Paradigms are generally held as "*they advance assumptions about the social world ....and what constitutes legitimate problems, solutions and criteria of proof*" (Creswell 1994 p1).

A mixed method research design has historically been perceived as controversial "*due to the incompatibility of the paradigms that underlie the methods*" (Tashakkori & Teddlie 2003 p18). This has sparked 'paradigm wars' and for many years proponents of qualitative or quantitative research paradigms have fought for supremacy with 'purists' from each of the paradigms arguing that their approach is superior (Lincoln & Guba 2000). The quantitative paradigm is associated with positivist assumptions, is objective in nature with hypothesis testing and the researcher is distant from those being researched (Schrag 1992). In contrast the qualitative paradigm is underpinned by interpretivist or constructivist traditions with multiple constructed realities. The researcher is intrinsically involved in the research process and an inductive approach is used to generate the findings (Cresswell et al 2003).

Purists from each paradigm attest to its supremacy and argue that "*qualitative and quantitative paradigms have entirely different goals, different uses of research methods, and the need for different criteria to fit with each paradigm….. one cannot mix research methods across qualitative and quantitative paradigms*" (Leininger 1994 p101). Purists attest that qualitative and quantitative methods should not be mixed as they originate from differing ontological and epistemological positions (Bryman 1984, Tashakkori & Teddlie 2003).

In contrast, pragmatists argue that quantitative and qualitative approaches can be combined with the research question determining the methods that are used as "*epistemological purity doesn't get the research done*" (Miles & Huberman 1984 p21). Mixed method research has been proposed as a third paradigm, bridging the divide between quantitative and qualitative research and utilising the inherent strengths from both (Onwuegbuzie & Leech 2005). Howe (1988, 1992) argues that although certain research methods have been associated with a particular paradigm this should not be the case and researchers should be free to use the most appropriate method. Additionally, the use of multiple research methods can enhance understanding of the research area. Johnson and Onwuegbuzie (2004) and Onwuegbuzie and Leech (2005) highlight that qualitative and quantitative approaches actually display congruity as both attempt to understand individuals and their world.

4.4.1 Position adopted in this research

The researcher found the paradigm debate surrounding the use of mixed methods challenging due to the variety of stances held by different researchers (Creswell et al 2003, Greene & Caracelli 2003, Teddlie & Tashakkori 2003). After extensive reading the researcher opted to use the clear framework provided by Morse (1991, 2003) to determine the paradigmatic approach. Morse (1991, 2003) states that in mixed method research it is essential to recognise the theoretical drive of the study. Morse et al (2006) defines the theoretical drive as "*the overall inductive or deductive direction of a research project that guides the use of the appropriate qualitative and/or quantitative methodological core*" (p281). If the purpose of the research is

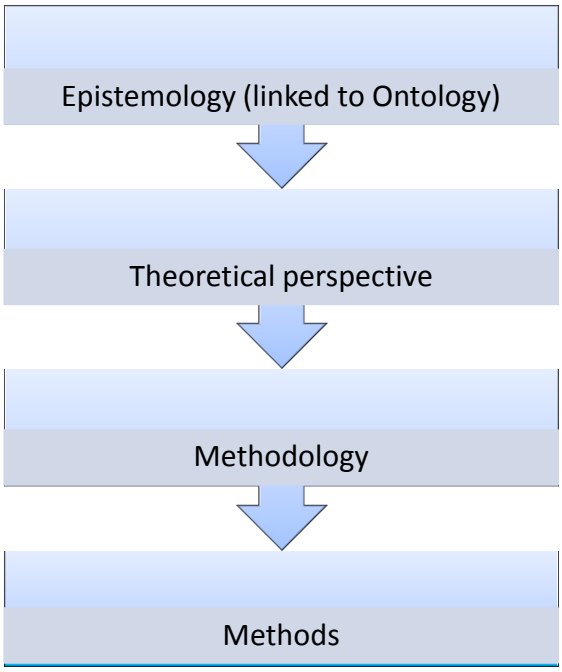
"*to describe, or discover, to find meaning or to explore*" (Morse 2003 p193), then the theoretical approach will be inductive. The methods used are more likely to be qualitative in nature, although quantitative methods can be used for 'exploratory purposes' with an inductive approach. If the purpose of the research is to test a hypothesis or theory then the theoretical approach is deductive and the methods used are likely to be quantitative (Morse 1991).

As this research study will explore a little researched area where there is limited understanding, an inductive approach was deemed appropriate. The purpose of this research study is to discover and explore the factors that influence nutritional recovery in patients after critical illness. This will ultimately result in the generation of a theory by moving from real life contexts to generalisations through abstract concepts, a process that again highlights the need for an inductive approach. In addition the researcher realised through undertaking the exploratory study (Chapter 3) that the qualitative component was far greater than originally anticipated and should inform the overall approach to the research. Recognising the importance of the qualitative inquiry in the research process the researcher made the decision not to mix the paradigms, instead approaching the research inquiry from the qualitative paradigm. Adopting this approach meant that it was simply the methods that were mixed, this will be described in more detail later in this chapter.

4.5 Mixed method research design

Lewis (2003) highlights a number of important elements that need to be considered to ensure a good research design. These include a clearly specified purpose for the research study, connection between the research questions and methods or approaches used. The data generated is valid and reliable and consideration is given to the practical issues of time and monetary constraints and also to the reality of the research setting. Crotty (1998) recommends when developing a research proposal that careful consideration is given to four interrelated elements that inform one another: epistemology, theoretical perspective, methodology and methods (figure 9). The arrows indicate the relationship of the elements, not the order that the decisions were made.

Figure 9: Research design elements (adapted from Crotty 1998)



Crotty (1998) suggests that the choice of methods will determine the methodological approach. The choice of methodology reveals the theoretical perspective which in turn has an inherent epistemology. Lewis (2003) highlights the importance of a connection between the research questions and the methods and methodology. A critique of Crotty's approach is that his model is linear when in reality the qualitative research process is inductive and iterative.

The researcher's research design was driven by the research questions which evolved from the exploratory study with the methods and methodology linked to these. The theoretical perspective and epistemology then became apparent. However, in order not to disrupt the natural flow of the doctoral thesis the research design is not presented in this order, instead the epistemology is detailed first, then the theoretical perspective, methodology and finally the methods.

4.6 Ontology and Epistemology

As an early career researcher the concepts of ontology and epistemology were difficult to understand, especially when dealing with mixed methods research which

has long debated the problems of linking epistemology and methods (Howe 1988). Crotty (1998) suggests that ontology should be addressed at the same time as epistemology since both influence the theoretical perspective. The researcher admits to grappling with both these constructs whilst appreciating their importance in the research design. Once the researcher had made the decision to approach her research design from a qualitative paradigm, based on her findings from the exploratory study, this helped to clarify the philosophical assumptions underpinning this study.

4.6.1 Ontology

Crotty (1998) suggests that ontology should be discussed at the same time as epistemology as both inform the theoretical perspective. Ontology is defined as "*the study of being*" (Crotty 1998 p10) and is concerned with the nature of existence. It questions the nature of reality and what we can know about it (Illing 2010). For this doctoral research a relativist ontological position was adopted and patients described their experiences, what it was like for them and this formed their reality. Relativism assumes the existence of multiple realities that are constructed by individuals and their views of the social world (Guba & Lincoln 2000).

4.6.2 Epistemology

Epistemology is concerned with knowledge and how we understand things. Crotty (1998 p8) describes epistemology as "*providing a philosophical grounding for deciding what kinds of knowledge are possible and how we can ensure that they are both adequate and legitimate*". There are a number of differing epistemological positions that attest to different views of knowledge. The three widely recognised epistemological stances are objectivism, subjectivism and constructionism (Crotty 1998). The rationale for the researcher's decision to reject objectivism and subjectivism and use constructionism as her underlying epistemological stance is provided below.

4.6.2.1 Objectivism

Objectivism subscribes to the belief that objects in the world have meaning, whether or not we are consciously aware of them (Crotty 1998). Objectivism is associated with a positivist theoretical perspective and as such asserts that 'facts' can be gathered about the social world and this leads to the discovery of objective 'truth' (Illing 2010). It is assumed that the researcher is a detached observer who investigates the phenomenon without having an effect on it or it influencing the researcher (Wilson 2000). This approach is traditionally associated with quantitative methodologies and methods and used to inform biomedical research (Crotty 1998). Although objectivism is a common epistemological stance within the health service, the researcher has rejected this approach as she recognises it would not enhance the research design as the study looks to understand the patients' perspective of eating, how they feel about it and what influences it. Coming from a health service background the researcher acknowledges that her perspective has changed through undertaking her background work. She became increasingly aware that her objective beliefs failed to capture the process of nutritional recovery and she would need to adopt a different approach.

4.6.2.2 Subjectivism

Subjectivism as the second epistemological stance attests that knowledge is subjective and there is no objective truth (Wilson 2000). "*The researcher and the object of the research are assumed to be linked by the values of the researcher and relevant others who influence the study. Findings or knowledge are value dependent; they are mediated by the values of the researcher and the relevant others*" (Illing 2010). In essence the object of study is not involved in the construction of meaning; this is established by the researcher (Crotty 1998). The researcher noted during her reading in the area of epistemology that subjectivism was often not mentioned, with objectivism and constructionism described as the main epistemological stances. This perhaps reflects the fact that subjectivism is becoming less popular with qualitative researchers.

4.6.2.3 Constructionism

The third epistemological stance, constructivism rejects the other views of knowledge and attests that knowledge is socially constructed (Illing 2010). "*Meaning is not created but constructed out of the world that is already there, and objects in that world. The world and its objects may have no intrinsic meaning, but they are partners in the generation of meaning*" (Illing 2010 p288). Culture influences how we see the world and shapes our views (Crotty 1998) and the researcher "constructs an image of a reality" through interactions with participants (Charmaz 2000). Meanings are co-constructed with different participants constructing meaning in different ways (Crotty 1998).

This study aims to explore patients' experiences of eating after critical illness and looks to gain an increased understanding of the factors that influence nutritional intake. Therefore the use of constructionism as the underlying epistemological stance fits with the research aims. Guba and Lincoln (1989) argue that researchers cannot be separated from the participant, therefore the research should provide an understanding of the constructions that are held by both about the area of the study. Individuals' experience of eating after critical illness differs, which will influence their behaviour and beliefs, and the researcher as a clinical dietitian also has her beliefs and perceptions about nutritional intake post ICU.

4.7 Theoretical Perspective

The theoretical perspective chosen provides the philosophical stance that underpins the research methodology (Crotty 1998). "*The theoretical perspectives are the starting point from which assumptions about the research are based; they influence how the study is conducted, the researcher's role and the type of knowledge that is produced*" (Illing 2010 p284).

4.7.1 Interpretivism

Interpretivism is the theoretical perspective that has been adopted for this research study. The interpretivist approach "*looks for culturally derived and historically situated interpretations of the social life world*" (Crotty 1998 p67). Interpretivism is

linked to '*Verstehen*' or understanding (Weber 1968) and within the context of this research, the study aims to provide an understanding of patients' experiences of eating after critical illness and how this affects nutritional intake. One aspect of interpretivism is symbolic interactionism.

4.7.2 Symbolic interactionism

Charmaz (2006) argues that "*symbolic interactionism is a constructionist perspective because it assumes that meanings and obdurate realities are the product of collective processes*" (p189). Symbolic interactionism is accredited to the work of George Herbert Mead in the 1930s and that of his student Herbert Blumer who elucidated Mead's theories. Blumer (1969 p2) identified three principles that underpin symbolic interactionism:

- Human beings act towards things on the basis of the meanings that the things have for them.
- The meaning of such things is derived from, and arises out of, the social interaction that one has with one's fellows.
- These meanings are handled in, and modified through, an interpretive process used by the person dealing with the things he encounters.

Essentially these principles of meaning, language and thought are intrinsically involved in the creation of 'self' which is a product of social interaction, constantly evolving through engagement in society (Jeon 2004). Mead (1934) argues that self is made up of 'I', which is not influenced by others, and 'me' that sees 'self' as a reflection of what others see. 'I' and 'me' are in constant dialogue before the individual acts or displays a behaviour. Through a process of self-reflection and interpreting others' actions individuals form a 'social self'. This concept of a socially constructed 'self' is important for the study in terms of exploring how patients interpret their identities in light of their altered relationship with food, changes to their body and interactions with healthcare staff, family and friends.

Bulmer (1969) maintains that "*human group life or society exists in action and must be seen in terms of action*" (p6). In order to understand the participants' world the researcher needs to examine actions and interactions. Hence the researcher needs to be involved in the participants' world and this can be done through observation (Jeon 2004). Using this principle for the study, the researcher needs to understand the patients' experiences on the ward in relation to eating and the impact of interactions with others. In order to do this the researcher has to ascertain what is happening and how interactions with others influence the process of nutritional recovery.

4.8 Methodology

Grounded theory was the approach that was used in this research study and the researcher will provide justification for this choice. It is interesting to note that Strauss, one of the founders of grounded theory, was trained in the Chicago School of Sociology where he was influenced by a number of proponents of symbolic interactionism, hence grounded theory is theoretically informed by symbolic interactionism.

4.8.1 Evolution of grounded theory

Grounded theory originated from work carried out by sociologists Glaser and Strauss in the 1960's. Their collaborative efforts in a study exploring the process of dying in terminally ill patients (Glaser & Strauss 1965) resulted in the publication of the book "*The Discovery of Grounded Theory*" which describes the strategies employed in their original research (Glaser & Strauss 1967). Grounded theory is a methodology for developing a "*theory that was derived from data, systematically gathered and analysed through the research process*" (Strauss and Corbin 1998 p12). Glaser and Strauss (1967) challenged the supposition that qualitative methods were unable to produce new theory and were strong advocates for qualitative research being a methodological approach in its own right.

Grounded theory effectively amalgamates the depth and richness of data associated with qualitative research with the logic and rigour from quantitative methods (Dey 1999, Charmaz 2000). Elliot and Jordan (2010 p30) highlighted that "*the overall aim in grounded theory is to generate theory inductively by gathering data about a phenomenon, identifying the key elements and then categorising the relationships of those elements to each other*". A key component of grounded theory is the use of the constant comparative method where data collection and analysis occur concurrently in a process of constant comparison of data with data, data with category, category with category and category to concept (Glaser & Strauss 1967).

4.8.2 Approaches to grounded theory

During the last 40 years grounded theory has evolved and has been taken in different directions which led to debate about what constitutes grounded theory (Charmaz 2000). This was fuelled in part by a differing of opinions between the co-originators of grounded theory Glaser and Strauss. This difference of opinion became public knowledge when Strauss collaborated with Corbin to produce their version of grounded theory (Strauss & Corbin 1990). This was contested by Glaser (1992) who argued that it was not grounded theory and labelled it a new method called 'full conceptual description'. From this point grounded theory has become synonymous with Glaserian or Straussian approaches (Stern 1994). Regardless of which approach is employed, both versions attest to the same research process: collect data, code, compare, categorise, theoretically sample, develop a core category and generate a theory (Walker & Myrick 2006). However, notable differences are apparent in the underpinning philosophical perspectives (McCann & Clark 2003a).

The Glaserian and Straussian approaches to grounded theory are positioned in one of the five moments of qualitative research history. Denzin and Lincoln (1994, 2005) defined these five moments as the traditional period, the modernist phase, blurred genres, crisis of representation and the final phase which represents the present. The Glaserian approach to grounded theory was founded in the second moment, the modernist phase, and was informed by a realist stance. Realist ontology assumes the existence of an objective reality where the researcher is independent from the

research (McCann & Clark 2003a). Strauss and Corbin's approach to grounded theory assumes an objective reality but is considered post positive as it gives a voice to the respondents (Illing 2010). Their approach is a combination of post positivism and constructivism as they highlight the importance of maintaining the researcher's objectivity yet also "*emphasise that it is not possible to be completely free of bias*" (Strauss & Corbin 1998 p97).

More recently grounded theory has evolved further as Charmaz developed a constructivist grounded theory (Charmaz 1990, 2000, 2002, 2006). This approach allows the researcher to "*move grounded theory methods further into the realm of interpretive social science consistent with a Blumerian (1969) emphasis on meaning, without assuming the existence of a unidimensional external reality*" (Charmaz 2000 p521-522). Constructivist grounded theory studies reposition the role of the researcher from an impartial observer to a co-constructor of meaning with participants (Mills et al 2007). A constructivist approach requires the researcher to create a sense of reciprocity with participants and alleviate the power imbalance (Mills et al 2006). This requires the researcher to assume a more reflexive position and these issues are addressed in light of this research study later in the chapter.

Despite the different variations in grounded theory that reflect contrasting ontological and epistemological underpinnings, all ascribe to a number of common elements. These include:

- simultaneous data collection and analysis
- early data analysis to elicit emerging themes
- discovery of basic social processes through the data
- inductive construction of categories that explain and synthesize these processes
- sampling to refine the categories through comparative processes
- integration of categories into a theoretical framework (Charmaz 2002 p677).

4.8.3 Methodological issues associated with grounded theory

There are a number of methodological problems that are associated with the use of grounded theory and these can "*limit research outcomes*" (Elliot and Jordan 2010 p29). A number of these issues have been identified in the literature and include failure to describe the underlying epistemological approach (McCann & Clark 2003a), failure to use theoretical sampling, analysing the data after finishing data collection instead of using constant comparative analysis (Becker 1993b), forcing analysis of the data in the early stages of the research (Cutcliffe 2005), fragmented coding instead of developing an overarching concept (Atkinson & Delamont 2005) and failure to generate theoretical concepts (Morse 2004). The researcher took these potential issues into account when designing and undertaking her research and in this thesis aims to provide the reader with a clear account of the research process.

4.9 Alternative methodological considerations

The researcher opted to use a constructivist grounded theory approach, where data and analysis are constructed by interactions with participants and other sources of data to create a conceptual framework from categories 'grounded' in the data. As the purpose of the study was to explore the factors that influence nutritional intake in patients after critical illness and create a new theory from the concepts arising from the study, a grounded theory approach was considered the most suitable. A variety of other methodological approaches were critically appraised and rejected in favour of grounded theory, these are discussed below.

4.9.1 Case study

As previously mentioned in chapter 3 a case study approach was considered initially for this study. Case studies are indicated when the research questions focus on “how” and “why” questions (Yin 2003). It is useful strategy when multiple data collection strategies are required and can incorporate a combination of qualitative and quantitative methods (Yin 2003). Similar to case study, a grounded theory approach can incorporate data from many sources. However, differences in the two approaches are apparent when looking at the goals of each method. The purpose of

the case study is to describe a contemporary phenomenon within its real life context (Stake 1995, Yin 2003). The researcher realised she needed to go beyond what a case study was able to do in order to address the purpose of her research. By adopting a grounded theory approach it would allow the construction of theories that explain a phenomenon and represent another's views (Wimpenny & Gass 2000). This construction of theory is consistent with the recommendations from the Medical Research Council which highlight the need to develop theory prior to further work (MRC 2000). The use of grounded theory methodology would be ideal preparation for subsequent work intended to evaluate interventions to address the issues raised in this doctoral thesis.

4.9.2 Phenomenology

A phenomenological approach was also considered for this study as it is useful in providing an understanding of human experiences (Wimpenny & Gass 2000). Vivilaki and Johnson (2008) advocate the use of phenomenology if the research question is related to human experience. Phenomenology and grounded theory share these characteristics as both focus on human experiences and aim to understand a phenomenon from the participants' view point (Baker et al 1992). However, there are a number of fundamental differences between the approaches. These include difference in research strategies as phenomenology describes psychological structures and grounded theory explains social processes (Baker et al 1992), phenomenology commonly uses interviewing as the method of data collection but grounded theory approach allows multiple methods to be employed; data analysis in phenomenology allows the researcher to gain an insight into the lived experience of a phenomenon but does not result in theory generation (Corben 1999). A phenomenological approach was rejected for this research study on the basis that it did not allow for the explanation of social processes or easily incorporate multiple methods. It also does not allow the generation of a theoretical framework which was one of the purposes of the study.

4.10 Method

Morse (2003) highlighted the lack of congruence between grounded theorists over the most suitable data collection methods for this approach. When interviews are used as the sole method of data collection the focus can shift from the social processes occurring over time to the lived experiences of participants (Benoliel 1996). Glaser (1992) suggests that data collection methods should include interviews and observation in order to elicit the meanings of the participants. Glaser and Strauss (1967) also highlight that quantitative methods can be incorporated into a grounded theory approach stating that "*each form of data is useful for both verfication and generation of theory..... in many instances, both forms of data are necessary - not quantitative used to test qualitative, but both used as supplements, for mutual verification and as different forms of data on the same subject, which, when compared will each generate theory*" (p18).

As previously mentioned a mixed method research design has been adopted for this study. Mixed method research has becoming increasingly popular among healthcare researchers as using a variety of methods offers increased understanding of the complex nature of illness (Morgan 1998). A mixed method approach has evolved from an increasing emphasis on more culturally sensitive research (Tashakkori & Teddlie 2003). This approach uses multiple methods of data collection with methods drawn from 'within method' approaches or 'between methods' approaches (Creswell 1994).

4.10.1 Definition of mixed methods

Morse (2003) provided clarification of the various terminology associated with multiple methods. Qualitative and quantitative studies that can stand alone but are combined in a research program are referred to as a multimethod design. This is defined as "*the conduct of two or more research methods, each conducted rigorously and complete in itself, in one project. The results are then triangulated to form a comprehensive whole*" (Morse 2003 p190). The use of qualitative and quantitative methods in a single study is defined as mixed method design which involves the "*incorporation of various qualitative or quantitative strategies within a single*

project that may have either a qualitative or quantitative theoretical drive. The 'imported strategies are supplemental to the major or core method and serve to enlighten or provide clues that are followed up within the core method" (Morse 2003 p190).

It was apparent that even the terms used to denote a mixed method study varied across the literature (Cresswell et al 2003). Some of the different terminology adopted by researchers included: interrelating qualitative and quantitative approaches (Fielding & Fielding 1986); methodological triangulation (Morse 1991); combining qualitative and quantitative research (Bryman 1988, Cresswell 1994) and mixed methods research (Green et al 1989). The key component in all these terms was the combination of different methods and therefore this researcher has opted to use the term mixed methods and the definition proposed by Morse (2003).

4.10.2 Strengths and weaknesses of mixed method designs

Morgan (1998) highlighted the strengths of mixed methods as it allowed multiple concepts to be captured within one research project. Mixed method design "*is a term that is applied when research strategies are used that are not normally described as part of that design…..to increase the scope and comprehensiveness of the study*" (Newman et al 2003 p192). Mixed method designs provide a broad, conclusive understanding of the research topic and minimises the limitations associated with the use of a single method, which are imposed by the method itself. Since the supplementary data are not studied in as much detail as they would be if it was the main method, verification of this data is achieved using the data from the main study (Morse 2003).

However, in attempting to provide a comprehensive understanding of the research problem a mixed method design can be questioned as lacking rigour. The supplemental data may be perceived as 'thin' with insubstantial findings. Other constraints of using mixed methods include the necessity of methodological expertise and the complexity of data management, analysis and presentation (Onwuegbuzie & Teddlie 2003).

4.10.3 Rationale for combining methods

Greene et al (1989) described five reasons for combining data collection methods. These are highlighted below:

1. Triangulation – aims to substantiate results using different methods.
2. Complementarity – aims to capture different aspects of a phenomenon to provide a more detailed understanding of the phenomenon.
3. Development – aims to use the results from one method to refine a subsequent method.
4. Initiation – aims to discover new perspectives, reformulating questions from one method with results of the other method.
5. Expansion – aims to extrapolate the breadth of a study by using different methods to investigate different aspects of the study.

The researcher used qualitative and quantitative methods in a complementarity mixed method study. This allowed the researcher to "*measure overlapping but also different facets of a phenomenon, yielding an enriched, elaborated understanding of that phenomenon*" (Greene et al 1989 p258). Greene et al (1989 p259) also states that complementarity can be used to enable "*elaboration, enhancement, illustration, clarification of the results from one method with the results from the other method*". Morgan (1998) highlighted that one of the problems with such a wide ranging definition is that it allows the rationalisation of broad research objectives. The advantage of this approach is that it increases construct validity as a result of maximising the strengths and offsetting the biases of each method (Rossman & Wilson 1985).

4.10.4 Mixed method research design

Hanson et al (2005) highlights that the design process for a mixed method study involves an additional three stages compared with traditional research designs. The three extra stages include choosing whether to use a specific paradigm, determining the data collection process and how and when to integrate the results. These stages will be described in more detail below:

4.10.4.1 Use of a specific paradigm

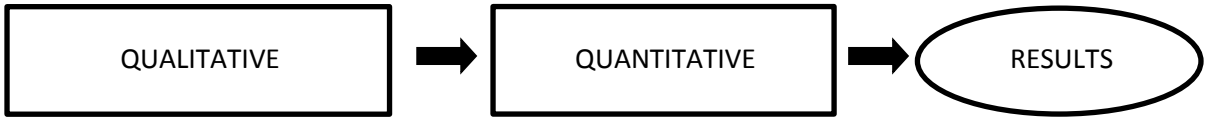
This issue has already been addressed at the beginning of the chapter and the decision made to adopt an inductive approach based on a qualitative paradigm.

4.10.4 2 Determining the data collection process

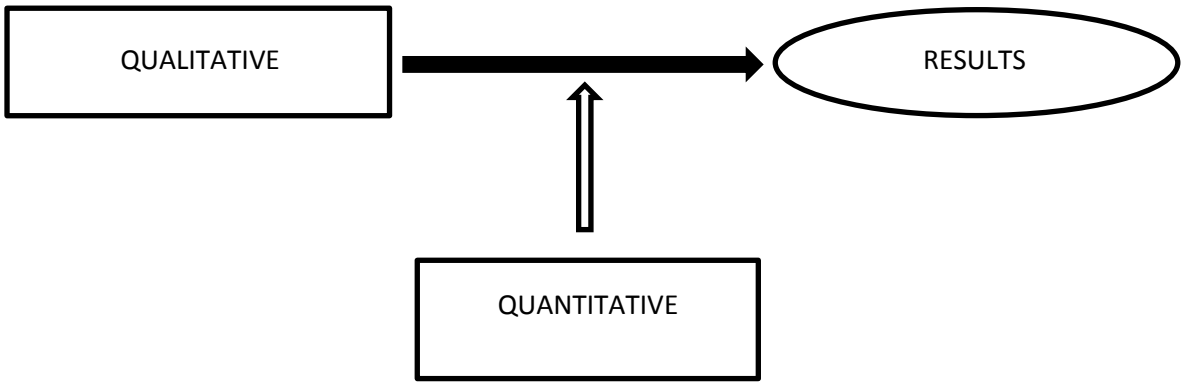
The second stage involves deciding which order the qualitative and quantitative data are collected, either concurrently or sequentially. It also relates to the priority given to each method, either equal or unequal (Creswell et al 2003). A variety of guidelines have been created to facilitate this process with the creation of visual models and 'notation systems'.

4.10.4.2.1 Visual models

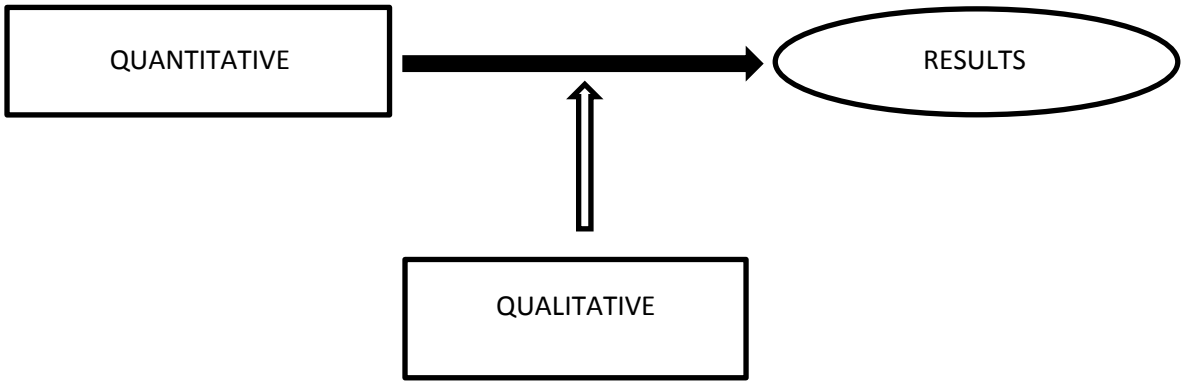
Steckler et al (1992) provided four approaches to combining qualitative and quantitative methods. The four ways are detailed below:



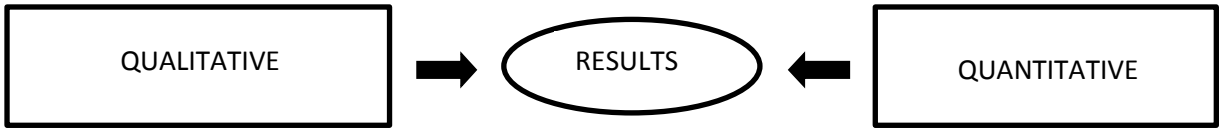
Model 1. Qualitative methods are utilised to aid in the development of quantitative measures.



Model 2. Qualitative methods are employed to facilitate the interpretation of quantitative results.



Model 3. Quantitative methods are used to provide further elaboration of qualitative findings.



Model 4. Qualitative and quantitative methods are given equal importance and are used side by side.

4.10.4.2.2 Notation systems

Morse (1991) developed a notation system that has been adopted by many mixed method researchers. Morse (1991) proposed four approaches to data collection which are described below:

1. QUAL+quan – simultaneous collection of data where research is driven by an inductive approach with the theory developed with qualitative methods complimented by quantitative methods.
2. QUAN+qual – simultaneous collection of data where research uses a deductive approach to refute or confirm an existing theory. This approach uses predominantly quantitative methods and may be complimented by qualitative methods.
3. QUAL→quan – sequential collection of data where research uses an inductive approach based primarily on qualitative methods.

4. QUAN→qual – sequential collection of data where research uses a deductive approach based primarily on quantitative methods then uses a qualitative method to examine unexpected results.

Morse (1991) argues that qualitative and quantitative approaches in a study cannot have equal weighting therefore the research is theoretically underpinned by qualitative methods which encompass a complementary quantitative method or underpinned by qualitative methods encompassing a complementary qualitative method.

For this doctoral study the researcher carried out concurrent collection of the qualitative and quantitative data using an inductive approach with the theory developed with qualitative methods complimented by quantitative methods. This would correspond to either model 3 of Steckler's (1992) visual models or approach number 1 of Morse's notation system. Using quantitative supplementary methods in a qualitative study offers increased understanding about what is happening in the data and also provides additional insights about what is going on (Morse 2003).

In this study the qualitative interviews and observations were the main data collection methods with quantitative data in the form of weekly estimates of patients' nutritional intake and visual analogue scores used as supplementary methods. The information from the latter two data sets was used to augment the findings from the qualitative data. A more detailed account of the methods used in this study is provided in the next section in this chapter.

Morse (2003) highlights the importance of recognising the role of the supplementary component in the research project. Often the supplementary component, which as previously mentioned is the quantitative component in this study, provides information that would not be obtained from the main methods. However the researcher needs to demonstrate understanding of how the two data sets interact (Morse 1991).

4.10.4.3 How and when to integrate the results

The third stage involves deciding at what point in the research process the 'mixing' of methods occurs: the data collection, analysis or interpretation phase (Creswell et al 2003). Hanson et al (2005) highlights that data can be analysed and integrated by "*analysing the data separately, by transforming them, or by connecting the data in some way*" (p227). In this study the qualitative and quantitative data were analysed separately using the principles from the underlying methodology which is grounded theory and then combined in the interpretation phase. A more detailed explanation of the data analysis is provided in the analysis section later in this chapter.

4.11 Data collection methods

As previously mentioned a variety of data collection methods were used in the study. The researcher had previous experience of using the quantitative methods but had undertaken further academic training to develop her skills in using qualitative methods.

4.11.1 Overview of Methods

- A nutritional assessment was performed on discharge from ICU and then at 3 months post ICU discharge, using Subjective Global Assessment.

- Patient food diaries were used to assess food intake in relation to estimated nutritional requirements on a weekly basis during ward stay and then at three months post ICU discharge.

- Visual analogue scales were used to provide weekly measurements of patients' experiences of pain, fatigue, weakness and appetite during the patients ward stay and also at three months post ICU discharge.

- Patients were observed on the ward three times a week and information about the management of their rehabilitation and process of recovery was also

collected from medical and nursing notes. All factors impacting on nutritional recovery were recorded in a case report form (Appendix 4).

- Patient interviews were carried out after discharge from ICU and weekly for the duration of their ward stay. Patients were invited to take part in a semi-structured interview at 3 months post-ICU discharge, either at home or in the Clinical Research Facility based in the hospital. The interviews focused on eliciting patient's experience of eating after critical illness.

Each of these methods is described in more detail below.

4.11.2 Quantitative methods

4.11.2.1 Nutritional Screening

The researcher assessed patients on discharge from ICU and at 3 months post ICU discharge using a nutritional screening tool which "*utilizes the clinical judgement of a practitioner to identify patients at risk of or with malnutrition*" (Keith 2008 p410). This technique uses the Subjective Global Assessment (SGA) tool which was developed over 25 years ago by Baker et al (1982) (Appendix 2). It incorporates historical, symptomatic and physical parameters to determine nutritional status (Jeejeebhoy 2000). The results are then used to classify patients into three categories: normally nourished, moderately malnourished or severely malnourished. For the purposes of the study the researcher categorised patients into two groups, well-nourished or malnourished with the malnourished category including moderately malnourished and severely malnourished patients. This was done to allow comparisons to be made between the two groups during the interpretation phase of the research process.

Nutritional assessment is notoriously difficult in the early post ICU phase as the large shift in body fluids associated with the presence of ascites and oedema make measurements of weight inaccurate (Campillo et al 2004). Limited mobility in many patients after critical illness makes it difficult to carry out anthropometric measures

and functional measures such as handgrip strength are also influenced by the effects of critical illness (Douglas et al 2000).

The SGA has been widely used as a clinical nutrition screening tool in a wide range of patient populations including patients with HIV (Niyongabo et al 1999), post-liver transplant patients (Stevenson et al 2001), chronic renal disease (Steiber et al 2004, Jones et al 2004), elderly patients (Sacks et al 2000) and critically ill patients (Sheean et al 2010). In many studies it has been used as successfully as a range of objective measures including biochemical indices such as albumin, triceps skinfold thickness (Baker et al 1982, Detsky et al 1984). SGA has undergone extensive testing for validity, reliability, specificity and sensitivity hence is accredited with the most 'diagnostic value' for acute patient populations (Kubrak & Jensen 2007). The disadvantage of the SGA is that it requires significant training prior to its use.

4.11.2.2 Food Diaries

The use of food diaries in this study had a two-fold purpose. Firstly, the diaries were used to record food intake for each patient during the 3 month study period. While the patient was in hospital, food intake was recorded by the researcher. This was done retrospectively with the researcher asking the patient to recall their food intake over the previous 24 hour period. Where this was not possible, for example due to the patient experiencing delirium or confusion and therefore unable to recollect food intake, the researcher went to the ward at mealtimes to ascertain food intake. The food diary contains a number of sections to capture what the patient ate at breakfast, lunch, dinner, including an indication of quantity e.g. all, half or quarter portion (Appendix 5). There are also additional sections to incorporate the documentation of all snacks and drinks consumed within the 24 hour period. During the patients' ward stay, food intake was recorded for a three day period each week and an average was calculated to provide a weekly figure.

At three months post ICU discharge the patient was sent a three day food diary and this was collected by the researcher at the three month visit. The researcher asked that the record of food intake included one weekend day as it is recommended where

a recording period of less than 7 days is chosen, at least one day should be a weekend day as eating habits may differ (Thomas and Bishop 2007).

Average weekly intakes were then compared with calculated nutritional requirements to determine if these were being met. Calorie requirements were estimated using Schofield equation which is based on age and weight to provide an estimation of basal metabolic rate and then additional factors are added for activity and stress to provide an estimation of calorie requirements (Schofield 1985). Protein requirements were derived from an equation by Elia (1990) which again is based on weight. These predictive equations only provide an estimation of nutritional requirements however they are routinely used in clinical practice to provide a baseline against which the patient is monitored.

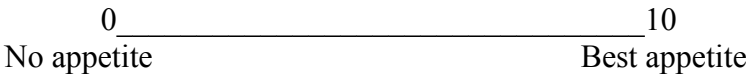
The food diaries had also planned to be used as a qualitative data collection tool where the patient was asked to record their experiences at meal times. However, it was found that patients struggled to complete the information due to the high levels of fatigue experienced and therefore this was abandoned.

Food diaries were used in the study as they are inexpensive, provide a direct measure of current diet and can achieve high levels of reproducibility (Nelson 2000). However, this method is also associated with a number of sources of bias as there are no completely objective measures of food intake as "*any measurement of diet will be biased in some way by the measurement process itself*" (Nelson 2000 p316). The reported diet may not reflect the actual diet as subjects choose to omit certain items or it may not reflect the usual diet as subjects may alter their dietary intake during the recording period to include more healthy foods and less foods regarded as unhealthy. Subjects may also simplify their diet to make recording easier. These errors are in addition to those due to poor memory or inaccurate recording. All these factors commonly result in underestimation of dietary intake and hence raise construct validity issues (Thomas and Bishop 2007). However, for the purposes of this study the loss of quantitative accuracy is outweighed by the advantages of a method that was acceptable to the patient.

4.11.2.3 Visual analogue scales

Visual analogue scales were used to measure symptoms of breathlessness, appetite, pain and fatigue. Patients were asked to complete these scales on discharge from ICU, weekly during hospital stay and then at three months post ICU discharge.

A visual analogue scale (VAS) is "*a measurement instrument that tries to measure a characteristic or attitude that is believed to range across a continuum of values and cannot easily be directly measured*" (Gould et al 2001 p706). The VAS consists of a line which is usually 100mm in length. At each end of the line words describe the minimum and maximum extremes of the characteristic being measured with the low end to the left on a horizontal scale or the bottom on a vertical scale (Gift 1989). Individuals are asked to mark on the line at the point they feel indicates how they are currently feeling. The score is ascertained by measuring the distance from the left hand end on a horizontal scale or the bottom of a vertical scale to the point marked by the individual (Gould et al 2001). An example of one of the visual analogue scales used in the study is shown below.



The VAS is quick and simple to design and easily understood by participants (McCormack et al 1988). Gould et al (2001) highlights that VAS measurements are subjective and are most effective when looking at individual changes rather than making comparisons across a group at a set time point.

The researcher used the quantitative methods to provide an indication of patients' nutritional state, food intake and subjective measures of a number of dimensions thought to be affected as a result of their critical illness experience.

However, these measures do not provide an explanation of how or why patients' eating was affected after critical illness. In order to provide an understanding of patients' experiences of eating after critical illness, the qualitative methods of

interviews and observation were used to capture the processes that influence nutritional intake.

4.11.3 Qualitative methods

4.11.3.1 Interviews

Interviewing is one of the most commonly used data collection methods in qualitative research (Mason 2002). Holstein and Gubrium (2004 p 140) describes the interview process as a way of "*generating empirical data about the social world by asking people to talk about their lives*". Interviews can provide large amounts of data within a short timescale. By focusing on a restricted number of topics and eliciting detail, this allows for an increased depth of understanding. Researchers commonly have a list of main questions, probes and follow up questions to ensure that the topic is sufficiently covered (Rubin and Rubin 2005). Coupled with observation, interviews enable the researcher to "*understand the meanings people hold for their everyday lives*" (Marshall and Rossman 1995 p81). Interviews necessitate the co-operation on the part of the interviewee however they may be reluctant to disclose information. The interview method is highly reliant on the interviewee's ability to express, interact, formulate and recall their understandings (Mason 2002). It is also assumed that interviewing provides a true and accurate picture of the respondents' life, however interviewing only provides a construction or reconstruction of the respondent's perceptions (Fontana and Frey 2000).

4.11.3.1.1 Types of Interviews

There are many different types of interview with the term 'qualitative interview' used to denote structured, semi-structured, indepth or unstructured forms of interview. It could be argued however that structured interviews used a questionnaire-like format with a limited set of response categories and hence are more quantitative in nature (Fontana and Frey 2000). During the researcher's deliberations as to which type of interview to use for her research she found a paper from Wimpenny and Gass (2000) that indicated that there may not be a 'typical' grounded theory interview. Charmaz (2006) argues that methods are merely 'tools' and the most important factor is to

ensure that they enable the collection of rich data to generate grounded theories. Rich data are "*detailed, focused and full, they reveal participants views, feelings, intentions, and actions as well as the contexts and structures of their lives*" (Charmaz 2006 p15). Patton (1990) states that unstructured interviews allow the participant to tell their story which is important during the initial stages of grounded theory research (Glaser and Strauss 1967). However, Mason (2002) argues that all interviews are structured in some form. When conducting semi-structured interviews the researcher asks more specific questions, initiating the discussion and uses prompts to guide the interviewee (Duffy et al 2004). Semi-structured interviews combine structure with flexibility allowing the researcher to utilise prior knowledge during the interview process but also focus on issues of significance and explore comments made by the respondents (Legard et al 2003). Duffy et al (2004) concluded that both unstructured and semi-structured interviews are appropriate data collection methods in grounded theory research. In the initial stages of the research an unstructured interview approach is commonly adopted with semi-structured interviews used further into the study guided by more focused questions from the emerging concepts (Strauss 1987). As highlighted from the exploratory study (Chapter 3) a semi-structured approach to interviews was adopted for this patient group.

The format of the interview questions followed the suggestions from Charmaz (2006) who recommends three stages to the interview: opening, intermediate and ending stage. An introductory question such as 'Can you tell me how you ended up in ICU? was designed to help the patient to feel at ease from the outset of the interview. Intermediate questions were more specific and included "Can you tell me how your eating has been this week" or "Is there anything that has made eating more difficult for you this week?" Ending questions were used to draw the interview to and close but also to allow the patients to highlight any additional issues that they felt were important. Patients were asked "Is there anything else that you think might be relevant?" Further examples of interview questions are included in appendix 3.

The researcher was aware of the potential problems associated with fluctuating levels of delirium in this patient group (McNicoll et al 2003). Patients were therefore screened, prior to each interview, for the presence of delirium using the Confusion Assessment Method for the Intensive Care Unit (CAM-ICU) tool (Ely et al 2001) (Appendix 6). Before starting the interview the researcher asked the patient the questions from the CAM-ICU tool such as 'will a stone float on water?' and 'there fish in the sea?'. Depending on the answers provided the patient is either scored delirium positive or negative. There was only one instance during the study period that a patient was assessed to be suffering from delirium. The researcher did not proceed with the interview and came back to the ward the next day and reassessed the patient who was then found to be delirium negative.

4.11.3.2 Observation

Observation has been described by Marshall and Rossman (1995 p 79) to "*entail the systematic noting and recording of events, behaviours and artifacts in the social setting chosen for study*". In this doctoral study the goal of the observation process was to examine ward culture and how this may impact on nutritional recovery. Use of observation as a method facilitates the discovery of complex interactions in social settings (Marshall & Rossman 1995) and it "*occurs in real time, in the context of the busy clinical environment with all its time constraints, pressures of work prioritisation and continual interruptions and distractions*" (McCaughan 2002 p98). Observation allows researchers to observe scenarios participants have highlighted in interviews and also provides information that can be followed up at interview (Marshall & Rossman 1995). DeWalt and DeWalt (2002) suggest that observation can be used for providing answers to descriptive research questions, theory building or hypothesis generation or testing.

During the study period the researcher visited the patient on the ward three times a week to carry out observations. The researcher had other patients in the study at the same time who were on different wards, so the visits had to be limited to three times a week for practical purposes. Information relating to nutrition was taken from the patients' medical and nursing notes. As highlighted by the exploratory study

mealtimes were of particular interest and the researcher observed breakfast, lunch and dinner times at different points during the patients' ward stay.

Observation is a method that requires a great deal of the researcher (Marshall and Rossman 1995). Silverman (2001) highlights a number of methodological issues in carrying out an observational study including gaining access, finding an identity, defining the research problem and recording observations.

4.11.3.2.1 Gaining access

For the researcher, as an NHS employee, the process of gaining access to the hospital setting which is typically viewed as a 'closed' setting' was simplified. Access was still subject to research governance and approval had to be granted from the ICU clinical director, the research and development office and from the ethics committee, this described in more detail in the ethical considerations section later in the chapter. The researcher, although in some senses was an 'insider' as she is employed as a clinical dietitian in the ICU at the hospital where the research is being carried out, was also an 'outsider' as she did not regularly go on to the wards. To gain access to the wards the researcher had to consider what identity she was going to adopt.

4.11.3.2.2 Finding an identity

The role of the researcher when undertaking the observations will influence her identity in the research setting. When deciding on what role to adopt she initially looked at the classic definitions from Gold (1958):

- the complete participant, who interacts within the social situation and they have a covert role
- the participant as observer, who interacts within the social situation, however they have an overt role
- the observer as participant, observes for a short period of time but also conducts interviews, their role is overt.
- the complete observer, does not interact within the social situation and their role is covert.

The researcher had intended to adopt Gold's last classification as a complete detached observer in order to minimise the effects of her presence on the data being collected. However, this did not always prove to be the case as a number of situations meant that this role changed over time. To overcome the difficulties with the classifications of the researcher's role provided from the literature, the researcher opted for Turnock and Gibson's (2001) approach of "*describing the actual observer's role rather than struggle to identify a not wholly appropriate descriptive label*" (p474).

The researcher found, similar to Pretzlik (1994) that maintaining one role was not always possible and the extent of the observer's participation cannot be determined from the outset of the study. The researcher is a clinical dietitian who, although working predominately within the ICU, has occasionally seen patients on the wards. Ward staff saw the researcher as a dietitian and she was able to observe patients at ward level using her professional identity. This did lead to the researcher being asked for some nutritional advice from nursing staff about a patient on the ward or being asked by the patients to get their supplements or snacks from the ward pantry. In the first instance the researcher explained that she was not the dietitian involved in that patient's care and was carrying out a study looking at patient's nutrition after ICU so suggested that the staff nurse contact the ward dietitian. In the second situation the researcher felt a professional responsibility to get the requested supplement or snack for the patient as it was an important part of their nutritional intake. The researcher recorded these instances as they demonstrated some organisational issues that affected nutritional care.

As previously mentioned the researcher opted to undertake covert observation where the participants are either not aware they are being observed or the researcher does not reveal precisely why they are being observed to minimise the risk of the participants changing their behaviour (Turnock & Gibson 2001). If the researcher was questioned by ward staff about what she was doing on the ward she explained that she was doing a study to look at patients' nutrition after ICU and had come to see how they were doing. The researcher's dietetic colleagues saw her on the ward,

however, while they were aware she was undertaking a study looking at nutrition after ICU, they did not know exactly what it entailed.

4.11.3.2.3 Defining the research problem

Silverman (2005) suggests the most important undertaking for observational studies is to narrow down the research focus by ascertaining the research problem. For this study the researcher's clinical knowledge and previous exploratory work provided clarity in defining the research problem. Observation of practice was chosen specifically to look at ward culture and service delivery. Schein (1985 p45) highlights that "*we simply cannot understand organisational phenomena without considering culture both as a cause and as a way of explaining such phenomena*". Understanding the culture of the organisation may facilitate understanding of the problems related to service delivery and the impact for the patient. Increasing importance has been attached to organisational culture as a way of explaining complex social phenomena (Marshall and Rossman 1995).

4.11.3.2.4 Recording observations

The observations made and documented are determined to a certain extent by how the researcher conceptualises the 'field' of study (Mulhall 2003). The researcher holds a similar view to that of Atkinson (1992) who stated that the field "*is something we construct both through the practical transactions and activities of data collection and through the literary activities of writing field notes, analytic memoranda and the like*" (p5). Mulhall (2003) highlights that the researcher's identity and the way in which they collect, record and analyse the data will be determined by their disciplinary interests and individual world view. The researcher acknowledges that her professional interests as a dietitian meant that she was attuned to potential nutritional problems on the ward that may not have been identified by a researcher without a background in nutrition. For example an observation of a patient during a physiotherapy session revealed that the enteral feed had been disconnected during the session following which there was a delay in restarting the feed. This meant that prescribed volume of feed would not be delivered and

therefore the patient would not receive the recommended amount of calories and protein.

Mulhall (2003) highlighted that researchers have individual techniques for recording their observations. These techniques have been classified in terms of the structure used in the observation with the two main types being structured or unstructured observation (Turnock & Gibson 2001). However, Altricher et al (1993) argue that combining these techniques to use some structure is beneficial as it provides a focus for the observation. This approach can help circumvent a common problem with observation where researchers attempt to record everything in their notes making analysis much more difficult and time consuming (Silverman 2005).

The researcher undertook more focused observations around mealtimes, ward rounds and patient/staff interactions. As data collection and analysis was a cyclical process the focus of the observations altered to allow verification of evolving analytic themes.

The researcher recorded her observations in a weekly case report form. The field note page was divided into two columns with the left hand column detailing the content of the observation and the researcher's insights and reflections relating to specific parts of the observation documented in the right hand column. The researcher wrote short hand notes during observations and then wrote a more detailed account after leaving the ward.

4.12 Achieving Study Rigour

4.12.1 Rigour

Regardless of the type of research, it is generally accepted that demonstrating rigour is a necessary part of the research process (Omwugebuzie & Teddlie 2003). Omwugebuzie and Teddlie (2003) state that "*rigour necessitates that researchers attempt to be fully accountable for their data collection, analysis and interpretive methodologies.....continually strive to assess and document the legitimacy of their*

findings" (p354). As the research inquiry adopts the qualitative paradigm, the researcher opted to use the criteria proposed by Lincoln and Guba (1985) to demonstrate legitimacy. Internal validity (which applies to quantitative research) should be replaced by 'credibility', external validity should be replaced by 'transferability' and reliability should be replaced by dependability (Lincoln & Guba 1985).

4.12.1.1 Credibility

In qualitative research the concept of validity or credibility "*requires understanding beliefs about the nature of reality*" (Coben & Crabtree 2008 p334). This research study has adopted interpretivism as a theoretical perspective and therefore the researcher needs to understand the patients' experiences on the ward in relation to eating and how interactions with others influence the process of nutritional recovery. To ensure credibility the researcher needs to provide "*a meaningful account of the complex perspectives and realities studied*" (Cohen & Crabtree 2008 p334). Koch (1994) argues that credibility is enhanced when researchers highlight their experiences and self-awareness plays an important role in this process. This was done by keeping a research journal where details of interactions were recorded incorporating the researcher's reaction to specific situations (Koch 1994). During the current study the researcher kept a journal and excerpts from it have been included in the thesis.

Triangulation is another way of increasing the credibility of qualitative research (Roberts 2006). In the current study a variety of methods of data collection were used including assessment of nutritional status, measurement of nutritional intake, measurement of a range of symptoms, observations and interviews. Use of observation increases the credibility of the research as it enables the researcher to have a greater understanding of the context of the study (DeWalt & DeWalt 2002). Credibility is strengthened by incorporating other methods such as interviewing or other quantitative methods (DeWalt & DeWalt 2002).

Koch (1994) highlights that another way of promoting credibility is to involve the patients by asking them to provide feedback on the constructs that emerged from the study. This addresses the issues of "*accurately reflecting the phenomena under study as perceived by the study population*" (Lewis & Ritchie 2003 p274). This can be done either formally or informally. Member checking is one formal method described in the literature, however Charmaz (2006) argues that the process of concurrent data collection and analysis alleviates the need for member checking in grounded theory studies.

4.12.1.2 Transferability

Three techniques to ensure transferability were employed in the study. Firstly, the researcher provided a detailed account of the focus of the study, a reflection on the researcher, the rationale for patient selection and the context from which the data was gathered (LeCompte and Goetz 1982). Secondly, triangulation, using multiple data sources to increase understanding, was used which strengthens transferability in addition to credibility (Merriam 1988). Thirdly, data collection and analysis strategies were documented in detail to provide a transparent record of the methods used in the study.

4.12.1.3 Dependability

Cresswell (1994) suggests that the dependability of the research is enhanced by addressing a number of issues. The research report should detail the researcher's positions including their assumptions and values. These components of reflexivity will be discussed in detail in the subsequent section. Other methods for increasing dependability include providing a description of those who provided the data and the social setting where the research was carried out. The theories and ideas that informed the research should also be detailed and finally an account of the methods used in the study should be provided (LeCompte and Goetz 1982).

In relation to constructivist grounded theory Charmaz (2006) suggests a number of criteria to ensure rigor. These are:

- Credibility - has the research achieved intimate familiarity with the setting or topic? Are the data sufficient to merit your claims? Have you made systematic comparisons between observations and between categories? Has your research provided enough evidence for your claims to allow the reader to form an independent assessment?

- Originality - do your categories offer new insights? What is the social and theoretical significance of this work? How does your grounded theory challenge, extend or refine current practice?

- Resonance - do the categories portray the fullness of the studied experience? Does the grounded theory make sense to your participants or people who share their circumstances? Does the analysis offer them deeper insights about their lives and worlds?

- Usefulness - does your analysis offer interpretations that people can use in their everyday worlds? Can the analysis lead to further research in other areas? How does the work contribute to knowledge?

(Adapted from Charmaz 2006 p182-183).

In order to demonstrate that these criteria have been achieved, the reporting of the study necessitates a detailed description and explanation of the research process (Flick 2002) In addition Cooney (2011) highlights that "*researchers should trust in the grounded theory methodology and know that their studies will be rigorous if they apply the methodology correctly*" (p22). Most importantly the grounded theory should make sense and not require further explanation (Corbin & Strauss 2008).

4.12.2 Reflexivity

Reflexivity is important as it increases the credibility of the research and is fundamental when using qualitative methods (Jootun et al 2009). Reflexivity is defined as "*a critical self-reflection of the ways in which the researcher's social*

background, assumptions, positioning and behaviour impact on the research process..... and demands acknowledgement of how researchers (co)-construct their research findings" (Finlay & Gough 2003 p ix). Wilkinson (1988) identifies two different but interrelated forms of reflexivity: personal and functional and these are discussed below in relation to the current research.

4.12.2.1 Personal reflexivity

Using a constructivist approach the researcher *'constructs an image of a reality, not the reality*" (Charmaz 2006 p523) through interactions with patients. As such the researcher is an insider and co-constructor of the data. This sense of being an insider was also supported by the fact that the researcher is a dietitian in the hospital where the study was conducted. She has also undertaken background work in the area and has read the literature on nutritional care in hospital. However, she was also an outsider as her clinical remit is within the ICU and this meant that the ward setting was unfamiliar. This unfamiliarity with the setting helped the researcher to view interactions on the ward from a patient's perspective, instead of imposing her own preconceptions on the situation.

The researcher is the primary data collection instrument and hence their values, assumptions and behaviour can influence the research process (Finlay & Gough 2003). Researchers should demonstrate an awareness of how the presence of 'self' may impact the research, either intentionally or unintentionally. Sword (1999 p270) argues that "*reflection on the influence of self not only creates personal awareness of how the research is shaped by one's own biography but also provides a context within which audiences can more fully understand the researcher's interpretation of text data*". This recognition of the influence of self means that the "s*ubjectivity in research is transformed from a problem to an opportunity*" (Finlay 2002 p531). In essence how the researcher sees herself and how she is perceived by others can influence interactions with others in the study.

In the current study the researcher recognised that her values and beliefs have been cultivated by working in the National Health Service, an organisation that

historically has positivistic assumptions with an objectivist world view. Reflecting on the researcher's motivation for this study has led to the realisation of her frustration at the inability of her professional self to improve patient's nutritional intake using traditional objective nutritional interventions such as recommending nutritional supplements. The researcher admits a sense of involvement in, and obligation towards, improving nutritional care. This meant that the researcher had a real interest in the experiences of patients in the study. Although initially patients saw the researcher more as a professional, i.e. as a dietitian, than a researcher, their perceptions changed over the course of the study and she was viewed as someone who had time to listen to their stories.

The researcher found some of these stories to be very sad or raised feelings of frustration, these emotions and biases of the interviewer could have potentially have influenced what was asked and how the patient responds. Emotions influence the researcher's reconstruction of how participants think and feel and "*if we do not feel what participants feel, we expect at least to feel for them*" (Kleinman & Copp 1993 p28). Rubin and Rubin (2005) highlight that researchers need to continually examine their own understandings and reactions. The following excerpt demonstrates the researcher's reflections on a distressing interview.

JM: How do you feel about what's happened to you? Have you kind of had time to process it?

Patient 14: It's jist a blur. Aye. I dinnae understand it A dinnae understand what's happened. I dinnae. I don't know. A dinnae want to go back. I dinnae want to go back there, definitely no (talking about ICU).

JM: What's eating like for you at the minute?

Patient 14: A nightmare, I jist cannae eat. I dinnae want to eat and nothing tastes right. Everything tastes different. It's no the same eh.

Reflective memo: The patient was completely overwhelmed by her ICU experience and was struggling to cope emotionally. I felt so sad for her, she had been through so much and yet I can do nothing other than listen to her. I realised that although I could do nothing to help this particular patient, other than giving her a voice, the purpose of my research was to increase understanding of these issues and it was important that her story was heard.

The researcher identified with a reflective account from Sword (1999) describing her experiences in conducting a study of prenatal care among low-income women, revealed the variety of unanticipated feelings, such as sadness and anger, she encountered during the interview. Sword (1999) demonstrated self-awareness and focused on finding out the meaning the interviewees gave to their experiences, rather than allowing her personal views to shape the subsequent discussion.

4.12.2.2 Functional Reflexivity

This form of reflexivity relates to one's role as a researcher and the effects this may have on the research process. It highlights the different identities presented within the research and the impact of power dynamics and status on interactions between researcher and the participant.

4.12.2.2.1 Identity

Atkinson and Hammersley (1994) identified four problematic features relating to identity: whether the researcher is known to be a researcher; what and how much is known in relation to the research being carried out; what activities the researcher engages in and how this is perceived by the subjects; and also the researcher's awareness of 'self' and how much this is adapted to fit the setting.

Hallowell et al (2005 p70) acknowledged that "*identity management is a fact of life – we do it all the time*". This is evident in the research context where the researcher has deliberately highlighted or concealed an aspect of their identity. In the current study, although the patients knew the researcher was a dietitian, she deliberately chose not to emphasise this aspect of her identity and instead highlighted her identity as a PhD student researcher. This was done to encourage patients to describe all aspects of their experiences and not just the physiological factors which are the focus of dietetic consultations and also reduce the risk of patients telling the researcher what they thought she would want to hear.

Whilst undertaking observations the researcher used her professional identity and was seen as a clinical dietitian rather than a researcher. Although some of the staff,

particularly the ward dietitians were aware of the research study, the researcher was reluctant to explain the research in detail in case practice was altered. Roth (1970 p278) highlights that "*all research is secret in some ways and to some degree – we never tell the subjects everything.....So long as there exists a separation of role between the researchers and those researched upon, the gathering of information will inevitably have some hidden aspects even if one is an openly declared observer*"

Many studies in the literature have employed identity management in order to benefit the research process. In a study by Knox et al (2000) which explored issues faced by people with an intellectual disability the researcher revealed that she was parent of a child with learning disabilities and a divorcee. These attributes gave her credibility in the eyes of the interviewees who saw her 'as one of them' and this facilitated rapport and creation of shared meanings. Another example of identity management is provided by Sword (1999) who deliberately chose not to reveal her professional background as a nurse, and instead highlighted her student status with a desire to learn from the interviewees' 'expert' knowledge. Sword (1999) acknowledges that the way in which she portrayed herself to interviewees played a beneficial role in engaging them in the research process.

Identity management is not without its problems however, and this is demonstrated in a study by Hoddinott and Pill (1997) that looked at how women decided to feed their babies. Some participants were aware that the researcher was a General Practitioner (GP) and others were not. It was found that interviews were easier when the participants knew that the researcher was also a GP, however managing both identities was difficult as the interviewees often sought medical advice during the interview.

In the current study the researcher also had to manage her identities and the following excerpt highlights the interplay of the researcher's different identities and the reflexive process maintained throughout the study.

Patient 3 wife: He's just no got the appetite. It doesnae matter what you try and kindae suggest or well you ask him you know what he would like, what he would

fancy to eat and then, I bought last week, I had got quite a lot of things in and a lot of them was wasted 'cause they ended up you know.

Patient 3: But like it's no like I'm dain it on purpose if you're no….

Patient 3 wife: (interrupts) Well no.

JM: Well that's the thing if you're not….

Patient 3: (interrupts) If you're no feeling like it, and I know myself that I should be but it's one thing saying it and another thing dain it. I just wish that I could ….well I am sure I will get my appetite back and maybe you could suggest something to start putting some weight on.

(Doorbell interrupts interview and wife goes to answer door)

Patient 3: It's my wife you see, sometimes she gets upset.

Reflective memo: It was clear that there was a tension between the patient and his wife. She was clearly frustrated that he wasn't eating despite everything that she was doing and he was feeling pressurised by this but trying to remain positive. I realised that he was asking for my professional advice, particularly for the benefit of his wife and this was important for both of them.

In this situation the researcher acted as a dietitian and gave the nutritional information as requested. Similar requests for nutritional advice were made from another three patients at the three month follow up interview. There were a number of other occasions where the researcher was seen as a source of information. An example of this was from patient 5 during an interview on the ward. The patient admitted that she was concerned about her inability to concentrate as she had tried to read a book and struggled to get past the first page. She described herself as a book worm and highlighted that reading was a hobby she had previously loved. The researcher reassured the patient that this was a common problem after critical illness and highlighted the evidence that describes impaired concentration levels during the early stage of their recovery (Jackson et al 2009). By doing so the research 'normalised' this experience for the patient and she expressed her delight that this was only a temporary problem. The researcher was aware that giving advice posed an inherent risk of distorting her role yet felt that it would be unethical not to give the requested information. Classic work by Oakley (1981) discussed the boundaries between collecting data and giving advice. Oakley (1981) argued that the giving of

information reduces the exploitative nature of interviewing and also promotes 'rapport' between interviewer and interviewee.

4.12.2.2.2 Power

Power dynamics in the research setting are not often acknowledged in the literature by qualitative investigators (Kvale 2006). However, it is generally assumed that the balance of power lies with the researcher (Mason 2002). Critics argue that this imbalance of power creates a "*depersonalising, exploitative and patronizing relationship*" (Limerick et al 1996 p 449).

When the researcher is also a health professional, this power asymmetry is heightened in a number of ways. Firstly, as highlighted by Holloway and Wheeler (1995), the patient may feel obligated to take part in the research because of a sense of duty. Secondly, the often quoted therapeutic benefits of a qualitative interview can potentially lead to exploitation if the researcher is tempted to ask inappropriate questions which result in interviewees divulging more information than they had anticipated (Richards & Schwartz 2002). As Alex and Hammarstrom (2008) acknowledge "*despite the best intentions, the interview situation may be experienced as, and may be in fact, a form of abuse*" (p170).

The researcher was concerned about these issues with her dual role as practitioner/researcher and was aware that in an interview situation a reflexive approach was important to appraise her own role. During the interview process the researcher adopted a collaborative approach in an attempt to reduce the effects of power. She was gentle in her approach, actively listened and encouraged the patient to speak, this facilitated the interview process and allowed co-construction of the accounts.

Work by Knox et al (2000) provides an example of this where "*research is conducted with people, rather than on them"* (Knox et al 2000 p49). The interviewees, people with learning disabilities, are seen as the experts and the interviewer as the learner. Knox et al (2000) highlighted that the key to the

collaborative approach is the development of rapport. This rapport was established in part by the interviewees being empowered to play an active role rather than a passive one and the interviewer adopted the role of facilitator rather than controller or dictator.

It could be argued that it was not possible for the interviewer to totally relinquish power however, as Alex and Hammarstrom (2008 p170) suggest, in the interview setting "*power is created and probably shifts*". Sword (1999 p274) noted that "*reciprocity lessened the hierarchical nature of my relations with respondents, yet I was aware of my inescapable power in my role as researcher*". The researcher admits there was a tension between her desire to relinquish power to allow a collaborative approach and her inbuilt professional self who usually drives the decision-making and maintains control.

The researcher acknowledges that since the patients participated in the qualitative interviews out with their normal hospital care, this could have inadvertently created a setting where this imbalance of power was heavily demonstrated. In an effort to minimise the effects of power the researcher gave patients the opportunity to choose whether they would like to return to the hospital or have the researcher come to their house. Interviews that took place in the patient's home allowed a shift of power to the interviewee.

4.13 Setting and sample

4.13.1 Location

The setting for the main study was a large teaching hospital in central Scotland. The 18 bedded ICU, where patients were recruited from, is classed as a general ICU which means that the population comprised of a mix of medical and surgical patients. This location was chosen due to the size of the unit which would ensure sufficient numbers for the study. It is also where the researcher is currently employed so access and recruitment of patients on discharge from ICU would be aided.

4.13.2 Access

The researcher is currently employed as a clinical dietitian working in ICU therefore access to this patient group was relatively straightforward. Permission to undertake the study had been granted by the Critical Care Clinical Director. As an NHS employee the researcher had easy access to the local critical care database which holds individualised patient information. Permission to use this clinical information to identify potential patients for the study was granted by Professional Lead for ICU.

4.13.3 Eligibility criteria

Inclusion:

- Patients who had received ≥48 hours of mechanical ventilation in the ICU and were ready for discharge to a ward.

Exclusion:

- Patients who would be discharged into pre-existing rehabilitation programmes e.g. stroke or liver transplant.

The inclusion criteria of ≥48 hours of mechanical ventilation was chosen as this population comprises 50% of all mechanically ventilated ICU admissions hence would ensure adequate numbers. Patients who were going to be discharged into pre-existing rehabilitation programmes were excluded this was likely to influence nutritional care. Local data shows that these patients comprise less than 10% of the current case mix.

Patients were recruited from a larger study, "Evaluation of a **Re**habilitation **Co**mplex Intervention for patients following Intensi**ve** Care Discha**r**ge", The **RECOVER** study (Appendix 7). The study used the same eligibility criteria as described above. The aim of the study was to evaluate the outcome of enhanced ward-based rehabilitation, compared to standard ward care, on patient's physical function at 3, 6 and 12 months after intensive care discharge. The intervention utilised a generic rehabilitation assistant (GRA) to deliver coordinated enhanced treatment to patients

throughout the hospital and provide support after hospital discharge, under the supervision of existing multidisciplinary teams. Patients were randomised into one of two groups:

- Intervention group: received standard ward-based care delivered by the NHS service with additional access to enhanced rehabilitation during ward stay and telephone contact after discharge, based around a GRA working with existing NHS clinical teams.
- Control group: standard ward-based care delivered by the current NHS service.

The GRA delivered an enhanced and coordinated rehabilitation under the supervision of the multidisciplinary specialists. Key elements of the rehabilitation included: weekly individualised goal setting with each patient in a range of areas. These goals were determined in conjunction with the patient on an individualised basis; a plan of exercises and nutritional interventions aimed at achieving the goals; regular screening for anticipated problems relating to nutrition and physical disability using tools agreed with physiotherapy, dietetics, occupational therapy, and speech and language therapy teams.

The doctoral study recruited a sub-population from the RECOVER study to explore the effect of a generic rehabilitation assistant on patients' nutritional intake after critical illness and the factors that influence nutritional recovery.

4.13.4 Sample

The current overall case mix of patients requiring mechanical ventilation in the ICU consists of 42% surgical patients, 48% medical patients, 8% liver transplant patients and 2% from obstetrics and gynaecology (local data). It was therefore envisaged that around half the patients recruited would be discharged from ICU to a medical ward, the other half to a surgical ward. The mean age of patients admitted into ICU in 2006/2007 was 55.6 years with equal numbers of males and females (local data). Hence it was likely that a similar proportion of males and females would be recruited, potentially including a higher percentage of older patients.

In this study theoretical sampling was used as advocated by Charmaz (1990, 2000) to enable data to be collected, analysed and emerging categories re-examined. Theoretical sampling occurs when the researcher has identified theoretical categories and then collects new data to expand and refine these categories (Strauss & Corbin 1998) in a process that involves coding, constant comparison and memo-writing (Charmaz 2006). Charmaz (2006) highlights that "*theoretical sampling pertains only to conceptual and theoretical development; it is not about representing a population or increasing the generalizability of your results*" (p101).

This means that at the start of the study the number of participants required to ensure sufficient data for saturation of categories cannot be predetermined. The researcher struggled with this concept as rigorous ethical requirements meant that sample size had to be stipulated before the study commenced. However, having undertaken the exploratory study, a number of categories emerged from analysis of data which the researcher wanted to explore further. The researcher chose an arbitrary sample size of 20 patients to fulfil ethical requirements. However theoretical saturation, defined as "*no additional data are being found whereby the sociologist can develop properties of the category*" (Glaser & Strauss 1967 p61), was achieved after recruiting 17 patients into the study.

4.13.4.1 Sample description

All patients who were approached for participation in the study gave their consent to take part. The sample consisted of 17 patients, 11 males and 6 females. The patients ranged in age between 20 to 94 years with a median age of 55 years. The median length of ventilation days was 19. Five patients were transferred from ICU to a surgical ward, the remaining 12 to a medical ward in the hospital. Nine patients were in the intervention group of the RECOVER study and eight were randomised into the control arm of the study. A more detailed overview of the study participants is provided in Table 10.

Table 10 Overview of patients

Patient	Age	Gender	Admitting illness	Length of ventilation (days)	Ward stay (days)	Discharge destination
1	20	Male	Acute pancreatitis	44	33	Home
2	39	Male	Pneumonia	6	14	Home
3	68	Male	Chest infection	6	8	Home
4	54	Male	Septic shock	41	33	Rehabilitation hospital
5	55	Female	Pneumonia	34	16	Rehabilitation hospital
6	31	Female	Pneumonia	9	7	Home
7	42	Male	Pneumonia	32	4	Home
8	59	Female	Pneumonia	4	5	Home
9	52	Male	Pneumonia	23	14	Home
10	69	Male	Hepatic encephalopathy	4	6	Home
11	93	Female	Upper airway obstruction	3	7	Home
12	70	Male	Out of hospital cardiac arrest	24	10	Home
13	70	Female	Chest infection	19	6	Home
14	50	Female	Acute pancreatitis	27	53	Home
15	68	Male	Peripheral vascular disease	13	23	Home
16	60	Male	Phaeochromocytoma	3	4	Home
17	50	Male	Acute pancreatitis	41	28	Home

4.14 Time Frame

Local data showed there would be 200 eligible patients annually. Assuming a pessimistic 30% recruitment rate (recent studies in the ICU have achieved a 50-70% recruitment rate) it was expected that 4-5 patients would be enrolled per month. Therefore it was anticipated that the study, including 3 months follow up, would require 8-9 months. Data collection commenced in January 2011 and finished at the beginning of September 2011.

The time frame of 3 months after ICU discharge was adopted as the majority of the patients would have been discharged from hospital; the median length of ward stay for the study patients was 10 days. The literature on functional recovery after critical illness suggests that functional disability is at its highest in the first three months

after ICU discharge and between 3 and 6 months after ICU there are considerable improvements in physical functioning (Herridge 2007, Van der Schaff et al 2008). The current study wanted to capture the problems patients faced with higher levels of functional disability and therefore follow up was carried out at three months post ICU discharge. The relatively short timescale also limits recall bias (Lewis 2003).

4.15 Ethical considerations

There were a number of ethical considerations identified in the research:

4.15.1 Ethical approval

Ethical approval was sought from the Scotland A Research Ethics Committee (Appendix 8). Approval was necessary from this research ethics committee as patients who are unable to give their consent were included in the research. In these cases consent was sought from the patient's nearest relative or welfare guardian. When the patient became competent to give consent, their informed consent was obtained. The researcher was aware from previous research in this patient group that the inclusion of incapacitated patients into studies had been deemed problematic by the ethics committee. Ethical approval was only granted if an ICU consultant took responsibility for assessing the capacity of the patients in the study, hence this was included in the ethics form for this study. As ethical approval had already been granted for the exploratory study, the researcher submitted a substantial amendment to the ethics committee to gain permission to continue on to the main study with the revised protocol.

On a practical note, as the intensive care unit is very research active, the researcher had to liaise with the Critical Care research team to ensure that potential patients or their families had not been approached on numerous occasions for inclusion in different studies. The research team consists of research staff who recruit eligible patients into the research trials that are being conducted in the ICU. As the researcher was recruiting her patients at the end of their ICU stay she consulted the research staff to check which other studies the patient had been recruited to.

To ensure that patients were informed about the proposed research, the researcher explained and discussed the implications of the study and distributed an information leaflet (Appendix 9). The patient was then given time to think about the study and encouraged to speak to other family members. Dale (2006) recommends this approach as it enhances research quality by ensuring transparency of purpose and methods.

The need for transparency was particularly important in this study as the researcher was aware that her role as a healthcare worker raised the potential for the exploitation of power. In the health service there are however stringent requirements relating to consent, which were designed to help protect the patient. These included a requirement for the researcher to: reveal their professional background; clearly inform potential participants that the research is not an addition to their medical treatment; and to reassure patients that refusal to take part in the research will not affect their care (Richards and Swartz 2002). The researcher also made it clear that the patient was free to withdraw their consent at any time during the study. In this instance, the researcher planned to ask the patient if the data already collected could be used in the study. In addition the consent form clearly stated that digital recordings and anonymised direct quotes may be used in future publications. The researcher also ensured that all patient data was anonymised and stored securely.

4.15.2 Ethical issues

Sword (1999) found that her discussions raised a number of concerns for the interviewees and there was a clear need for information. This presented her with an ethical dilemma as she had "*established her role as a researcher and yet felt a professional obligation to provide assistance*" (Sword 1999 p274). Hallowell et al (2005) have also identified this issue and argue that in this situation it would be wrong not to give the interviewee information.

In relation to this study the researcher was aware that as she was clearly identified as a dietitian in addition to her role as researcher, ethical issues could arise. From the outset it was envisaged that these were likely to centre round the need to give

information. The researcher felt that she had a professional responsibility to give necessary dietary advice if requested and this was provided for a number of patients at their three month interview. As noted by Daly (1992) the giving of information provides a means of 'giving back' to interviewees and upholding the reciprocal nature of interview relationships. Also, while the researcher was observing practice on the ward she felt that she has a duty of care to highlight any concerns to relevant healthcare workers. Such instances were recorded and actually served to enhance the data collected. Examples of this included a patient who had been transferred into a chair and needed assistance to get back into bed as he was so exhausted and no-one had come to help. Another patient in a side room was experiencing severe pain when the researcher went in to carry out an interview and so the researcher had to find a nurse to administer some pain relief. A further example was a patient who had been given the wrong supplements, ones that he did not like and therefore did not consume them.

4.16 Practical considerations

4.16.1 Personal safety

It was envisaged that due to physical limitations of some of these patients that a number of the three month interviews would take place in the patient's home. The advantage of this was that it would facilitate open and honest discussion. However, as the author was the sole researcher in the study it posed some potential safety issues. NHS Professional guidelines for lone workers were followed with details of the patient's contact details and the scheduled time of the visit was given to a colleague and the researcher telephoned her colleague before and after going into the patient's house. For two male patients who had known drug and alcohol dependencies, the researcher specifically asked them to come to the Clinical Research Facility, based in the hospital, for the three month follow up visit.

4.16.2 Patient safety

There was the potential for the interview process to raise some sensitive and distressing issues and therefore the provision had been made for the services of a

specialist ICU counsellor if necessary. One patient expressed a need for counselling and the researcher arranged this for him.

4.17 Data Analysis

Data analysis has been described as the "*process of bringing order, structure and meaning to the mass of collected data*" (Marshall and Rossman 1995 p111). The use of mixed methods posed a number of challenges for the researcher. The research produced large amounts of data and the researcher was faced with a number of issues relating to the complexities of qualifying the qualitative data, combining the different numerical and linguistic data, interpretation of the results from such data and presenting the findings.

Morse (2003) highlighted that when using mixed methods it is important to conform to the methodological assumptions of the main method and cautions against providing numbers to quantify 'how much' or 'how many' in a qualitative study, particularly if all the interviewees were not asked the same question. Morse (2003) also recommends working with as few data sets as possible therefore and suggests integrating the data obtained from the supplemental component into the main study.

In the current study the quantitative data sets were small as data was only collected from 17 patients recruited into the study. However, as grounded theory methodology uses theoretical sampling, the researcher's intention was not to obtain a sample size sufficient to provide representation of a population or statistical generalisability. Rather, consistent with the chosen approach theoretical sampling provided data to facilitate development of categories and concepts (Charmaz 2006). The researcher utilised Flick's (2002) approach to enable her to make pragmatic decisions regarding the saturation of concepts. Flick (2002) recommends stopping and reflecting on the data collected, compiling a list of the findings and determining which codes need further development in relation to the research question. Ultimately, the data collected needs to be adequate to allow the researcher to tell a plausible story (Melia 1997).

The quantitative data provided supplemental results that examined different aspects of nutrition, specifically nutritional status and intake, hence contributing the overall understanding of the phenomenon.

4.17.1 Analysis of quantitative data

4.17.1.1 Nutritional status

The data from the Subjective Global Assessment classified the patients into two categories: well-nourished or malnourished on discharge from ICU and again at 3 months post ICU discharge. A basic analytic strategy was employed to use data from the baseline and 3 months nutritional assessment measurements to divide patients into four groups: [a] patients who were well nourished and remained well-nourished, [b] patients who were well-nourished and became malnourished, [c] patients who were malnourished and remained malnourished and [d] patients who were malnourished and became well-nourished.

4.17.1.2 Nutritional intake

Patient food diaries provided information on dietary intake over the period from discharge from ICU to 3 months post ICU discharge. Patients' food intake during their hospital stay was calculated using the menu analysis information provided by supplier of the hospital meals. The three day food diary completed by the patient at 3 months post ICU discharge was analysed using CompEat, a software program for analysing dietary intake. CompEat's database contains 3555 foods and recipes and can provide a detailed report on a large number of nutrients. The researcher inputted the foods detailed in the food diaries into CompEat and this provided a daily total for calories and protein. These intakes then compared against calculated calorie and protein requirements using Schofield (1985) and Elia (1990) equations respectively. Calorie and protein intakes, as a percentage of nutritional requirements, were calculated during ward stay and then again at three months post ICU discharge.

The mean for each patient's calorie and protein intake as a percentage of their nutritional requirements was calculated for the duration of their ward stay and at

three months post ICU discharge. These mean figures were inputted into a database and descriptive statistical analysis was performed using SPSS, a statistical software program. As the data was abnormally distributed, summary statistics are presented as medians (1^{st}, 3^{rd} interquartile range) as opposed to means. The data was used to compare intakes across the four groups identified above. Also the intakes from the patients in the intervention and control group of the RECOVER study were examined.

4.17.1.3 Subjective measures of breathlessness, appetite, pain and fatigue

Visual analogue scales (VAS), which provide a measure of breathlessness, appetite, pain and fatigue, were collected on discharge from ICU, weekly during hospital stay and at three months post ICU discharge. A mean for each patient's subjective experiences of breathlessness, fatigue, pain and appetite was calculated for their ward stay and at three months post ICU discharge. This data was inputted into a database and descriptive statistical analysis was performed using SPSS. This was again used to compare the scores across the four groups and also between patients in the control and intervention group of RECOVER.

4.17.2 Analysis of qualitative data

4.17.2.1 Transcription

Proponents of grounded theory hold contrasting views about the necessity of recording and subsequent transcribing of interviews (Glaser 1998, Morse 1991). Glaser (1998) argues that it is unnecessary to record interviews however Morse (1991) stresses that this approach "*limits the ability of the researcher to use the participants' quotations and consequently the ability of the researcher to truly ground the study*" (p8).

All the interviews during the study were audio recorded by the researcher. The 37 ward-based interviews were transcribed verbatim by the researcher as these tended to be shorter in length. This was a laborious process although was beneficial in aiding the researchers closeness to the data as allowed her to capture not only what was

said, but also 'how' it was said and also allowed for documentation of the researcher's own feelings. The 14 three month interviews were sent to a transcriber in order to facilitate timely analysis of the data. However, the researcher listened to each transcript a minimum of three times to check the accuracy of the transcription and record any additional information in her research diary. Observational data during the ward phase of care was collected for the 17 patients and recorded in the case report forms (Appendix 4) providing a qualitative account with information from medical and nursing notes.

4.17.2.2 Computer Assisted Qualitative Data Analysis Software

Software has been developed to aid the process of qualitative analysis and the advantages and disadvantages of these software programmes have been widely discussed in the literature (Seale 2000, St John & Johnson 2000, Peters & Wester 2006). Use of a qualitative computer database has improved the laborious process of analysing data by hand, making it easier and quicker to analyse large amounts of data and provides a more visible audit trail (Davies 2007). However, a number of drawbacks to using of computer technology during analysis include the danger of distancing the researcher from the data thus influencing the way the data is seen and the meanings derived (St John & Johnson 2000).

The researcher had intended to use NVivo, a database that "*stores transcripted material and has powerful search and retrieve functions allowing researchers to handle very large data sets, perform complex searches at the touch of a button and organise material that might have been overlooked*" (Davies 2007 p206). However, the researcher found the programme difficult to navigate even after receiving training on the software. Despite initial attempts to use NVivo the researcher felt that it created distance between her and the data and lead to abstraction of the findings. Subsequently the researcher undertook data analysis by hand, using post it notes, highlighting sections, writing memos and making notes in the margins of transcripts, field notes and case report forms. Although this was arguably a more 'messy' process it allowed her to feel immersed in the data and provided a broader picture of

the data. The use of diagrams allowed visual representation of the codes and emerging categories as shown below.

4.17.2.3 Grounded theory analysis

Grounded theory lends itself to multiple methods of data collection aiding rigour in the research process and alleviating the warnings from Greenhalgh and Taylor (1997 p742) who highlighted that “it is simply not good enough to flick through the text looking for "interesting quotes" which support a particular theory”. In grounded theory, data analysis follows a clear process that starts with a basic description, then to conceptual ordering and finally to theorising (Patton 2002).

4.17.2.3.1 Coding

Data analysis using a grounded theory approach is a cyclical process that starts with coding of the data. Dey (1993) suggested that "*we break down data in order to classify it, and the concepts we create or employ in classifying the data, and the connections made between these concepts, provide the basis of a fresh description*" (p30). Coding provides a means for exploring the data and forms the connection between the data and the emerging theory (Charmaz 2006). Coding is an "*iterative, inductive, yet reductive process that organises data, from which the researcher can then construct themes, essences, descriptions and theories*" (Walker & Myrick 2006 p549).

The process of coding varies according to the grounded theory approach used. Glaser (1978) and Charmaz (2000) suggest a two-step process involving substantive and theoretical or initial and focused codes while Strauss and Corbin (1998) advocate a three step process using open, axial and selective codes. The researcher opted for Charmaz's approach as she was using constructivist grounded theory and hence a two-step process was followed.

The initial step in analysis is substantive or open coding where codes are attributed to parts of data that illustrate what each section of text is about. These codes are “*provisional, comparative and grounded in the data”* (Charmaz 2006 p48). Initially

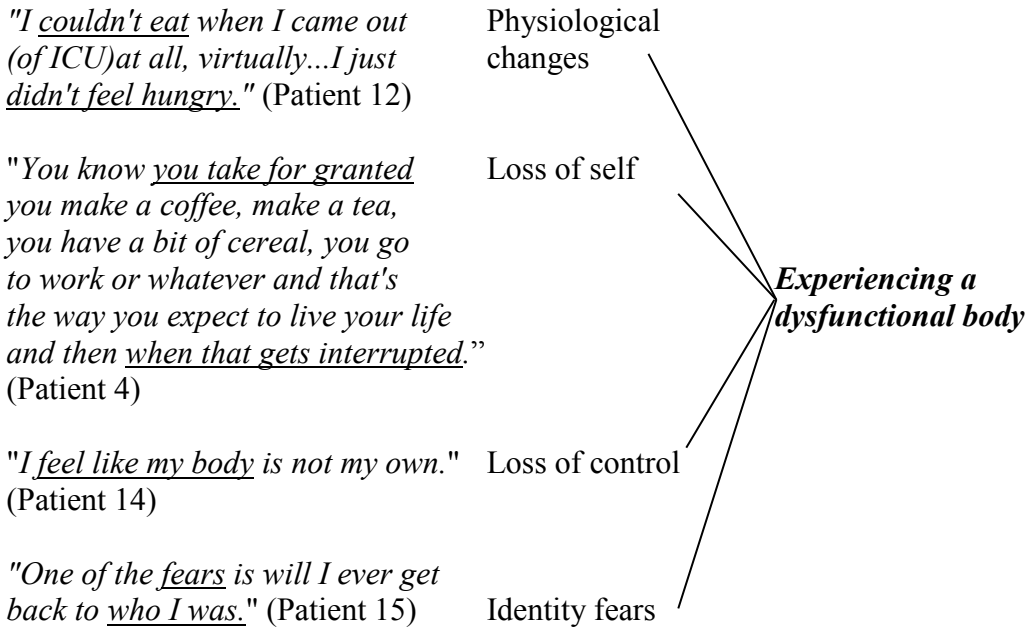
interview data is analysed using line by line coding which facilitates a focus on the data hence minimising the influence of any preconceptions (Charmaz 1990). Charmaz (2006) suggests that observational data is analysed incident by incident from the field notes looking for processes. In the current study the researcher looked for patterns in the data and coded them. Figure 10 gives examples of open coding from the interview transcripts.

Figure 10: Fragmentation of data and open coding

Data	Open Code
"*I'm eating because I have to..... I'm eating because it is necessary to live."* (Patient 16)	Eating out of necessity
"The *transition (from ICU to ward) is so marked that you almost feel as if you are being ignored completely, almost, not quite, but almost.*" (Patient 12)	Feeling ignored

The next step in analysis is theoretical or focused coding which starts to form explanations for larger sections of data through the creation of categories. This is a cyclical process as the researcher codes and recodes. Charmaz (2006) highlights that "*through focused coding you can move across interviews and observations and compare people's experiences, actions and interpretations*" (p59). Figure 11 shows an example of the process of open coding, focused coding and the evolving theoretical category.

Figure 11: Example of open coding, focused coding and development of a category



Through the process of constant comparative analysis and ongoing questioning of the data a core category emerges that explains the relationship between the other categories that have been identified (McCann & Clark 2003a).

4.17.2.3.2 Theoretical sensitivity

Theoretical sensitivity is a multifaceted concept that incorporates the researchers' understanding of the area being researched, ability to think inductively and reconstruct meaning from the data. Strauss and Corbin (1998 p59) highlight that *experience and knowledge are what sensitizes the researcher to significant problems and issues in the data and allows him or her to see alternative explanations and to recognise properties and dimensions of emergent concepts* (Strauss and Corbin 1998 p59).

4.17.2.3.3 Theoretical memos

Memo writing is a fundamental part of the analysis process and serve to "*catch your thoughts, capture the comparisons and connections you make, and crystallise questions and directions for you to pursue*" (Charmaz 2006 p73). This means that

the researcher records thoughts and ideas that evolve during analysis, a process which helps to construct the emerging theory (Elliot 2005).

4.17.2 4 Integration of the Quantitative and Qualitative Data

The quantitative data was integrated with the qualitative data during the later stages of analysis. The quantitative results were used inductively when looking at the qualitative data to ask "what is happening here?", "what does this suggest?" As previously highlighted it was envisaged that the used of mixed methods was for complementarity purposes to facilitate greater understanding of the phenomenon.

4.18 Unique Contribution to Knowledge

This study has provided unique insight into a little researched area, incorporating existing ideas where appropriate and identifying new connections with sociological concepts to provide an increased understanding of patients' experiences of eating after critical illness. Glaser (1978) highlights that "*theoretical codes give integrative scope, broad pictures and a new perspective this is why grounded theory is so often 'new' because of its grounded integration*" (p72). The researcher would argue that this study contributes a new understanding of patients' experiences of eating after critical illness by establishing the factors that influence nutritional intake and identifying the links between these factors based on concepts that are grounded in the data from post ICU patients.

4.19 Optimal research study

Reflecting on the main study the researcher recognises that limited resources and time constraints influenced the design of the research that was undertaken. The next section considers an ideal study design if there were limitless resources.

4.19.1 Ideal study design

As previously highlighted the process of nutritional recovery has multiple linked elements with the systems that deliver nutrition to patients superimposed on this.

The ideal study design would need to capture all the potential weak links in the chain that lead to nutritional recovery. It is entirely possible that a single break in the chain could disrupt the benefits from all the other elements. The ideal study would need to have a broad focus to capture all potential issues influencing nutritional recovery. If important issues were missed subsequent work could exert huge effort to no benefit. For example the use of innovative anti-inflammatory nutritional product designed to modulate the inflammatory response could be compromised if in practice patients were unable to tolerate it or if they never received it because of service delivery failures. The study would therefore add to the evidence base in line with the MRC framework and address the development element in the key elements of the developments and evaluation process (MRC 2008).

As a piece of health services research the methodology would need to be robust in order to capture context, heath service barriers and patient experience. Context is particularly important and the research would need to be undertaken within the NHS environment as other health care systems may fundamentally differ. Other contextual issues include how nutrition is delivered, the staff involved in delivering nutrition and the heterogeneity of the ICU patient population across different NHS hospitals. In order to encapsulate context and the issues influencing nutritional recovery a multiple case study approach would be an appropriate methodological choice as it inherently recognises the importance of context and facilitates information gathering from 'how' or 'why' questions (Yin 2003).

A case study is "*an empirical enquiry that investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used*" (Yin 1989 p23). Wells et al (2012) identifies the importance of understanding context when evaluating interventions and the potential problems associated with separating the intervention from the context. Case study methodology is most appropriate when there is a need to elicit a broad definition of a phenomenon providing a thick description (Yin 2003). In comparison, grounded theory allows an in-depth but

narrow investigation of phenomena and provides a generalised explanation of the social processes being studied (Glaser 2001).

In order to understand the process of nutritional recovery after critical illness a multiple case study approach could have been adopted. It is envisaged that the case studies would have been exploratory in nature in order to develop theory by describing the factors that influence nutritional recovery after critical illness. Additionally the case study approach could provide an understanding of *how* these identified factors influence nutritional care. The findings from the case studies would form part of the development process in developing and evaluating complex interventions (MRC 2008).

Crowe et al (2011) identify a number of important stages in the research process when carrying out a case study: defining the case, selecting the case, data collection and analysis, data interpretation and reporting the findings.

4.19.1.1 Defining the case

For the purposes of the optimal study the cases would be post ICU patients discharged to the ward in multiple NHS hospitals. A number of hospitals would need to be included in the study to capture different nutritional practices, service delivery issues, staff involved in delivering nutrition and the heterogeneity of the ICU patient population.

4.19.1.2 Selecting the cases

Purposive sampling would be employed to select the cases to explore the influence of different variables on nutritional recovery. Sampling would allow patients of different genders, ages, length of ventilation and ward destinations to be included in the study. Understanding the effects of the different variables on nutritional recovery would enable an intervention to be targeted at the most appropriate patient group.

However, although purposive sampling would be the optimal strategy, it may be very difficult to capture all possible situations and scenarios. Purposive sampling relies

on having the correct sampling framework and the researcher argues that adequate sampling strategies have not been designed for heterogeneous populations. Similarly the ideal sample size is difficult to determine but it is envisaged that 200-300 patients would need to be recruited to take into account attrition of patients over the study period and ensuring optimal transferability and dependability.

4.19.1.3 Data collection and analysis

To facilitate a detailed understanding of the case, multiple methods of data collection are commonly employed (Crowe et al 2011) as "*the case study's unique strength is its ability to deal with a full variety of evidence*" (Yin 2003 p8). For an optimal research study to explore nutritional recovery in post ICU patients it is envisaged that a mixed method approach would capture different perspectives. Quantitative methods including food diaries, anthropometry and body weight would provide an assessment of nutritional intake, nutritional status and body composition. Calorie and protein intake would be assessed on a weekly basis during ward stay and for a prolonged period after discharge, potentially up to a year post ICU discharge. Body composition measures would be taken monthly after discharge from ICU for 12 months post ICU discharge. This would allow for long term changes in nutritional intake, nutritional status, fat mass and fat free mass to be examined.

Qualitative interviews with patients, observation of ward practice and focus groups with staff would also be carried out. Patient interviews and observations would identify the nutritional problems experienced by patients after critical illness and observations of ward practice would highlight the organisational context that influenced nutritional care at ward level. Finally staff focus groups would elicit beliefs and attitudes that may affect nutritional care in this patient group. Patient interviews would also be carried at regular intervals after discharge from hospital for 12 months post ICU discharge to explore eating practices at home.

Analysis of the data would be undertaken in stages. Stage one would involve categorising patients into four groups using data from the baseline and 12 month nutritional assessment measurements. The four groups would be: [a] patients who

were well nourished and became malnourished, [b] patients who remained well nourished, [c] patients who were malnourished and became well-nourished and [d] those who remained malnourished. The qualitative data would then be used to explain the changes between the groups. Cases would be further subdivided by age, gender, ward speciality and patterns identified across the cases. Stage two would involve the qualitative data being subjected to an analysis independently from the nutritional data. This would determine what was linking the data and lead to useful and robust findings.

4.19.2 Reasons for not adopting ideal study design

The ideal study to explore the process of nutritional recovery would be hugely labour-intensive in terms of multiple detailed visits and interviews over a prolonged period of time in a large cohort of patients. To undertake research in such a heterogeneous complex population would require a huge study. It would be very challenging to analyse the vast quantities of data produced by a study that size. Accordingly the ideal study would also cost large amounts of money to carry out and this in itself is likely to be prohibitive.

In order to rationalise the time, resource and cost implications associated with the ideal study, the researcher chose to undertake a study that was achievable and analysable. With the period of study being time and resource limited, as is the case with doctoral work, the researcher opted to undertake a single site study in a large teaching hospital where she is employed as a clinical dietitian.

Recognising the need to capture context, heath service delivery issues and patient experience the researcher opted for a mixed method approach similar to that of the ideal study design. Time and resource issues limited the period of study to 3 months post ICU discharge instead of the 12 months suggested in the ideal study. The researcher argues that the shorter follow-up period still provided valuable data relating to nutritional recovery in the early period at home after discharge from the hospital.

The researcher opted to use a grounded theory methodology instead of the case study approach suggested in the ideal study design. The researcher argues that with the limited time and resources available using grounded theory methodology provided detailed data on a small number of patients in one setting and allowed the construction of theories that explain a phenomenon which is currently poorly understood. In light of the identified issues with purposive sampling in a heterogeneous population, the use of theoretical sampling advocated in a grounded theory approach allowed the researcher to achieve theoretical saturation in her study. Additionally, as previously mentioned in chapter 3 the researcher found that the analysis process in the case study approach was not clear and for a novice researcher the use of a grounded theory approach was helpful as the analysis process is well defined.

4.20 Summary of Chapter

This chapter has aimed to detail the research design the researcher has chosen for this study. Through explaining the theoretical position adopted for the research, methodological approach used and the methods employed it is hoped that the reader will have a clear understanding of the choices the researcher made.

Constructivist grounded theory was the methodology used to examine patients' experiences of eating after critical illness and the factors that influence nutritional intake. Use of grounded theory can incorporate a variety of methods and through this the researcher was able to use mixed methods to capture different aspects of the phenomenon. Interviews and observations were used to gain understanding of the patient's experiences and the underlying social processes. The researcher has provided a detailed account of how the study was conducted, the ethical processes involved and the process of reflexivity which is key to ascertaining the researcher's influence in the research inquiry.

The next chapter provides a narrative account of patients' experiences of eating after critical illness. It highlights the factors that influence nutritional intake during the patient's journey from discharge from ICU to three months after critical illness and

provides context for subsequent chapters that present an interpretation of the findings.

Chapter 5: Descriptive Account of Patients' Nutritional Experiences After Critical Illness

5.1 Overview of chapter

This purpose of this chapter is to describe the preliminary qualitative findings from analysis of the data that provide an account of the patients' nutritional journey during the first three months following ICU discharge. Using the stages of the patients' journey described in Chapter 1, patients' experiences of eating are explored at three time points: on transfer from ICU, during ward based care and after discharge from hospital.

5.2 Introduction

Detailing this account provided a means for the researcher to clarify her analytical thinking and formed part of the analysis process. Wolcott (2001) recommends that qualitative researchers begin writing early in the research process and highlights that "*writing reflects thinking, in fact writing is thinking*" (p22). This chapter also provides context for subsequent chapters that present an interpretation of the findings and generate theory.

The preliminary findings are from analysis of the data from 37 interviews provided by the 17 patients during their ward stay and 14 follow up interviews at three months post ICU discharge. Observations were also undertaken thrice weekly during the ward phase of care. The researcher observed ward practice for approximately an hour each visit. The focus of observation included activities such as food service delivery, monitoring of food intake, nursing handover, ward rounds and the delivery of supplements and snacks. Table 11 summarises the observation visits for each patient during their ward stay.

Table 11 Summary of ward observations

Patient	Number of observations	Total observation time (hours)
1	14	15
2	6	6
3	3	4
4	13	15
5	7	8
6	3	3
7	1	2
8	2	3
9	6	7
10	3	3
11	3	3
12	4	5
13	3	3
14	23	25
15	10	10
16	1	2
17	12	15

Using the data from the interviews and observations patients' experiences of eating are explored at three time points: on transfer from ICU, during ward based care and after discharge from hospital.

5.3 Transfer to the ward

5.3.1 Loss of desire to eat

When the patients in the study were transferred from intensive care to the ward they struggled to eat, especially during the first few days. This was a universal issue with patients reporting that they did not want to eat or felt they were eating out of necessity. The quotes below illustrate this:

"*I just cannae eat..... I just find it hard. I don't know what it is.*" (Patient 8)

"*Just got to try to eat it.*" (Patient 6)

"It's on my mind the whole time that I must eat." (Patient 3)

"*I know I've got to eat to get better. It's just that I'm not eating enough.*" (Patient 13)

"*I'm eating because I have to..... I'm eating because it is necessary to live, to eat. You've got to get your dietary stuff, your nutrition, all the stuff you need to get by in life but it's a struggle now.*" (Patient 16)

Aye, 'cause you've got to eat. You have got to eat haven't you? You've got to eat to survive." (Patient 14)

These quotes were representative of the patients' views and highlighted the extent of the problems with eating that patients faced after critical illness. Eating was not a pleasurable experience; food was only consumed out of necessity to fuel the body. It was apparent that the meaning of food had changed and it was perceived as a chore.

5.3.2 Contrast with pre-hospital intake

The difficulties with eating at the time of transfer to the ward contrasted with their reported nutritional intake prior to admission to hospital. Thirteen patients reported that they had a good oral intake before being admitted to hospital. Six of these patients had an acute onset illness which resulted in their ICU admission and had no significant co-morbidities. The other 7 patients had underlying co-morbidities, although these had not affected their nutritional intake prior to hospital admission. The quotes below describe the patients' oral intake prior to admission to hospital:

"(I was eating) everything and anything." (Patient 3)

"*I did have a good appetite. I ate healthily.*" (Patient 5)

"*I was a good eat*er, *I enjoyed food.*" (Patient 12)

"*I'd say I ate pretty well.*" (Patient 4)

"*Alright, it was quite good, regular diet.*" (Patient 17)

These quotes reflect the contrast in food intake before hospital admission compared with patients' experiences of eating after critical illness. Eating was a normal part of their everyday lives, an activity that was taken for granted as it did not require much effort.

Four patients reported a poor oral intake prior to hospital admission. Three had alcoholic liver disease and were actively drinking prior to admission to hospital, this was illustrated by one patient who said "*I wasn't eating at all, I was just drinking*" (Patient 3). The other patient had significant co-morbidities which had led to weight loss and problems with eating for two or three years prior to hospital admission.

5.3.3 Physiological barriers influencing eating

Patients described a variety of physiological problems that affected their nutritional intake. These included a poor appetite, taste changes (particularly a 'metallicky' taste), early satiety and fatigue. The quotes below illustrate these issues:

"(My appetite is) not too great." (Patient 1)

"I don't have any appetite. I'm sort of force feeding myself." (Patient 5)

"I noticed that first couple of days when everything was tasting the same." (Patient 2)

"They gave me some soup and macaroni cheese, and I remember the first time I got the soup I almost spat it out because it was too salty. It was terribly salty." (Patient 12)

"..... *nothing tastes right, everything tastes different.*" (Patient 14)

"*I dinnae ken. Our taste buds are no the same..... my wife got a wee portion of chicken and pasta from Marks and of course normally I would love that and eh I couldnae. It was just burning my tongue.*" (Patient 3)

"(Food tastes) metallic, a bit metallic." (Patient 16)

"I'm just no hungry. I order it, looks nice on paper, I order it, it comes up, I sit and think that looks nice. One spoonful and I've had enough." (Patient 15)

*I think some of the time I used to find you just can't be bothered. You know, you get this food put in front of you and you sort of, and then you think I can't be bothered eating this..... and you are not hungry enough to make a go of it." (*Patient 12*)*

These physiological changes clearly made it more difficult for patients to eat and were associated with a reduction in food intake.

Five of the 17 patients were transferred to surgical wards and this group of patients described problems with nausea, vomiting and diarrhoea. This was particularly evident in four of these patients who had acute pancreatitis and were also receiving nasogastric feeding. Anti-emetics were administered for these patients but these were often prescribed as single doses or as required and not written up as a regular dose. The quotes below illustrate the presence of gastro-intestinal symptoms:

"(*I feel nauseous) usually when I sit up on my stomach.*" (Patient 1)

"I couldnae eat, I just, I don't know, I couldnae. I was trying but it was like you were eating and boking at the same time, trying to force yourself to eat." (Patient 14)

These physiological changes negatively impacted on patients' food intake and influenced their experiences of eating. It was speculated that all the highlighted physiological changes were associated with the changed meaning of food for this patient group.

5.3.4 Other issues influencing nutritional intake

In addition to the problems directly affecting nutritional intake, patients experienced a range of other issues on transfer from ICU as they adapted to their new environment. The issues described below highlight the impact of critical illness, both physically and psychologically.

5.3.4.1 Physical dependency

The patients had very little control over their environment or their situation, especially just after arrival to the ward from ICU when critical illness related physical disability was most apparent. Patients relied immensely on ward staff for their care and basic needs. Observations revealed a number of occasions during meal times when patients who were struggling to eat did not receive any assistance. Another problem was that some patients were not positioned correctly to eat, often lying too flat when they were eating, which resulted in food spillage. Physical debilitation also limited supplement consumption in some instances as the patient was unable to remove the straw from the plastic packaging and pierce the foil seal on the drink.

5.3.4.2 Psychosocial issues

Patients commonly expressed their concerns about the differences in ward care going from one to one nursing care in ICU, to a nurse who is responsible for a large number of patients, if not a designated number of patient bays. One patient described his experience as "*if you need something it doesn't happen because they are looking after somebody else and you have to understand that, but the difference is terrific..... you are suddenly taken from Intensive Care, you are suddenly taken from something where you are absolutely looked after every second of the day, even in the middle of the night and then you are suddenly plonked into something that is, you've got to alter your whole attitude. You've got to accept that it's totally different.*" (Patient 12)

Patients also had to adapt to an unfamiliar environment, sometimes in a four bedded bay with other patients who had no idea what they had experienced in ICU or in a side room where they were isolated with no one to talk to. One female patient who was transferred from ICU to a side room on the ward said "*I don't think it's really good for me psychologically because I'm quite a sociable person..... that's why I kept the door ajar.*" (Patient 5)

This meant that patients who were particularly debilitated felt that they struggled to get enough attention from the nursing staff and this instilled a feeling of helplessness and increased their anxiety levels. One patient noted that "*the transition (from ICU to ward) is so marked that you almost feel as if you are being ignored completely, almost, not quite, but almost.*" (Patient 12)

The difficulties patients faced in dealing with the huge change from ICU to the ward and the trauma of their ICU experience compounded by the physiological problems impacted on many aspects of rehabilitation including nutrition.

5.4 First Week On Ward

During the first week on the ward patients continued to describe similar physiological barriers to eating with on-going taste changes, poor appetite, early satiety and fatigue. There were also a number of other factors that were noted to affect nutritional intake.

5.4.1 Physical impact of critical illness

Patients described significant levels of physical debilitation after their stay in ICU, commenting on how weak their body was, how much weight they had lost and how tired they felt. The quotes below illustrate these issues:

"*I looked at myself in the mirror and got a hell of a shock.*" (Patient 5)

"*Tiredness, just sheer utter tiredness, even tiredness in eating, tiredness in doing things, tiredness in not being able to do the things I want to do.*" (Patient 12)

"*I said oh my God I'm never going to be able to walk 'cause I had a couple of fly tries coming from here to this seat and I was lucky I never broke my neck.*" (Patient 3)

"*It has just made me really weak.*" (Patient 8)

Physical debilitation affected eating as patients were observed to lack the strength and dexterity for the physical act of getting the food to their mouth and tired easily.

Patients with severe debilitation had weak facial muscles that meant that chewing was difficult and they opted for soft choices from the menu in order to facilitate their nutritional intake.

5.4.2 Pain

Issues with pain were mentioned in the first week and this could have been as a result of changes to pain medication from ICU or the fact that patients had to do more for themselves and were having more physiotherapy sessions. Observations highlighted that the presence of pain increased stress and anxiety levels and patients were unable to focus on anything else. One patient was in such severe pain during an attempted interview that the researcher opted to terminate the interview and went to find a nurse to administer some pain medication. Patients who were in pain were observed to consume very little food at mealtimes as the pain distracted them from eating.

5.4.3 Nausea and vomiting

Patients reported on-going problems with nausea and vomiting during their first week on the ward. Observations showed that nausea and vomiting was particularly prevalent in patients who were receiving enteral nutrition. This patient group had complex medical issues and it was unclear whether the presence of nausea and vomiting was a result of the patients' medical condition, enteral feed or a combination of both. Patients themselves associated the nausea and vomiting with enteral feeding as the quotes below illustrate.

".....it was that thing (nasogastric tube) that was making me sick, because I could feel it at the back of my throat." (Patient 14)

"*It's this tube, it irritates me and I'm just sick..... I eat a wee bit then I'm sick and this tube when I swallow.*" (Patient 15)

"*It (ng tube) fell out and then they just said leave it out and see how I go eating on my own..... I think it was actually making me sick.*" (Patient 17)

5.4.4 Psychological effects of critical illness

5.4.4.1 Anxiety/Fears

During the first week on the ward patients described their anxieties as they struggled to come to terms with the extent of their illness and the stark reality of the fact that they may have died. The quotes below illustrate patients' anxieties and fears that were experienced in the aftermath of critical illness:

"*I haven't had a chance to process everything. I think it will take me a long time because I keep trying to analyse things. I analyse, I go back and I try and analyse why I was there and so on.*" (Patient 12)

"*..... I dinnae realise how ill I was, or had been rather, that sort of shook me.*" (Patient 3)

"*I still have this fear that as I move on some of what nearly happened to me will become a bit starker and a bit scarier cause you know I can sit here quite glibly and say well I nearly died downstairs (in ICU). That's not really properly registered with me.*" (Patient 9)

"*You know you take for granted you make a coffee, make a tea, you have a bit of cereal, you go to work or whatever and that's the way you expect to live your life and then when that gets interrupted..... There's a lot of people who have been in worse situations than me but it doesn't help.*" (Patient 4)

"*I just dinnae understand. I dinnae. I cannae come to grips with what's happened, where I have been. I don't know, I jist dinnae ken.*" (Patient 14)

A number of patients appeared to have no real understanding of what happened to them as they had no recollection of their time in ICU and there was a gap in their memory from the time of their initial injury to when they were on the ward. Some were unconcerned by this as they did not want to know what had happened during their time in ICU, but for others there was a desperate need to fill in the missing bits of information. Patients appeared to be overwhelmed with processing these issues and food was not a high priority at that point.

5.4.4.2 Delirium

Some patients still had periods of fluctuating delirium and night and day are often mixed up. Other patients described recurring nightmares and some experienced an altered sense of reality where they were not sure what was a dream and what was real. All these factors increase feelings of anxiety and stress. The quotes below illustrate these issues:

"*I was having horrendous dreams and I'm having difficulty sleeping.....I've started to wonder now is that real or not real, you know, and that's what's scaring me.*" (Patient 5)

"*I've had two particularly deeply recurring dreams which I had to get my wife to convince me were just total rubbish..... I was convinced that they were the reality but unless she's lying to me they're not.*" (Patient 9)

"*I don't know what's real and what's not..... it does unsettle you..... I don't know what's right and what's not.*" (Patient 4)

Observations revealed that the presence of delirium meant that patients were unable to ask for additional snacks and supplements if they had not received them. They were also unable to recall what they had eaten, which led to lack of clarity regarding the adequacy of oral intake, if ward staff did not note and record the amount of food consumed on the food record chart.

5.4.4.3 Changes to sleeping patterns

Patients commonly described alterations to their sleeping pattern in the first week on the ward. This is a common problem after critical illness with some patients finding that they were sleeping for much longer, others described issues getting to sleep and others were waking up during the night on numerous occasions. This meant that patients typically slept for periods during the day. The need for sleep was also influenced by increasing physical demands during the recovery process. Many patients expressed surprise at their need for sleep during the day, particularly noted after any increase in physical activity, even something as simple as having a shower. The quotes below illustrate these issues:

"*One thing I notice is that I'm sleeping a lot, about 12 to 13 hours a night..... I'm not saying I'm sleeping perfectly. I'm waking a few times during the night.*" (Patient 9)

"*I've not been sleeping but I have been sleeping at all the wrong times. I'm dozing when it is time to waken up so they are having to wake me up at breakfast because I've not been sleeping all night.*" (Patient 5)

"*Not sleeping, two nights I didn't sleep at all. The night before last I slept about four hours, last night I think about three.....I'm so tired.*" (Patient 11)

"*I've given in (and taken sleeping tablets)..... it knocks me out really quickly but I usually waken up between 3 and 4..... and then I'm awake probably for quite some time and then I dose off again, and then of course the day staff come in quite early so I'm woken up again.*" (Patient 5)

It was hypothesised that disruptions to sleeping patterns meant that patients may not feel like eating at the set mealtimes and the inflexibility of the hospital routine made it very difficult to get food out with these times. Observations showed that patients failed to consume their prescribed snacks or supplements as they were often asleep between meals.

During the first week on the ward, faced with the complexity of all the issues highlighted, eating was not high on a patient's agenda. When questioned patients did make a link between eating and getting physically stronger and the quotes below demonstrate the connection patients made between nutrition and recovery.

"*Oh most important, on par obviously with your exercises, because the two, you cannae just have exercises or you would be exercising a skeleton. But you need your vitamins and you know the rest of it and marry the two together and that's you got a nice healthy person going out.*" (Patient 3)

"*Well I suppose it is like everything else, it's part of the bigger picture isn't it. If I don't get enough protein, carbohydrate, vitamins and what not then that's going to hinder my progress isn't it?*" (Patient 9)

Despite patients acknowledging the importance of nutrition to recovery, observations revealed that this was not corroborated through actual quantities of food consumed.

It was hypothesised that patients were unaware of how much they needed to eat to meet their nutritional requirements during the recovery process.

5.5 Other factors noted to influence nutritional intake during ward stay

5.5.1 Low mood/depression

Patients reported having a low mood and this was particularly evident in those who had a longer ward stay. Three patients had a very low mood and were subsequently started on anti-depressants. Interestingly, one of these patients was specifically prescribed the anti-depressant Mirtazapine because of its appetite simulating effects. Interestingly, patients themselves failed to make the connection between low mood and reduced intake although observations showed that those who had reported a low mood had a reduced nutritional intake. The quotes below illustrate the problems with low mood experienced by these patients:

"Aye my mood's low." (Patient 14)

"*I'm having a struggle but I don't like people to see me down. I try and put up a front*" (Patient 5)

"*I'm depressed in as much as I don't like not being well cause this is not a regular thing for me not to be well..... so that depresses me a bit and I get depressed because I cannae get up and go for a walk because I'm not physically up to it.*" (Patient 9)

"*(My mood) is up and down, it's up and down..... it's a mixture of frustration but also selfish and that's because I feel frustrated that I should be in so many ways, you know, counting my blessings.*" (Patient 4)

5.5.2 Food as a substitute for previous addictions

For those who previously had problems with addictive behaviours such as drugs, alcohol or smoking their nutritional intake actually improved during their ward stay as they would substitute their addictions with food. For example instead of having a coffee and a cigarette, patients reported having a coffee and a biscuit. In addition, as

they were unable to partake in their addictions their overall nutritional intake was actually better as they simply ate more. Also food was prepared and served for them making it easily accessible. The quotes below illustrate this:

"I miss smoking, having a fag and a cup of tea..... but I just have a biscuit instead." (Patient 2)

"*I've been eating a bit more, it is a new thing aye..... this is the most I've eaten I think for years. I suppose it's because I've not been smoking as well. I've nae intentions of smoking again so will eat more.*" (Patient 2)

5.5.3 Influence of family support on eating

The importance of family support in improving nutritional intake was apparent in the study. Many patients had additional snacks, and sometimes meals, brought in for them by relatives, food that was familiar to them and food that they liked. Family members were observed bringing food from the canteen for the patient at a time that was more suited to usual meal times. Also patients were taken down to the canteen for meals by their relatives and this also served to encourage intake as patients were taken out of the ward setting and eating became a social activity. The quotes below describe this:

"My wife and sister were bringing in tasty bites and things like that...it was that bad that the boy next door in the bed, he says, You better watch you are going to get mugged." (Patient 3)

"My wife was making homemade soup and bringing it up in a flask sort of thing and I like those Muller fruit corner yoghurts so I always had those in the morning. They weren't part of the menu if you like, so my wife brought them up and they stuck them away in the fridge." (Patient 9)

"*It's my sister, I mean she can what we call 'bake for Scotland'. She's a marvellous baker so she's making sure I'm taking what I'm supposed to*" (Patient 3)

"*My wife brings in cocoa every afternoon and sometimes if she'd been baking she would take in a slice of Belgian loaf and our daughter would bring in shortbread, things like that. I've got a fantastic family and I think that is a big help.*" (Patient 10)

"*Fruit, bits of chicken and that eh, ken chicken in a bag. Aye I get quite a lot of food brought in for me. I'm actually getting my tea brought in for me tonight. I think I'm getting mince and tatties brought in.*" (Patient 6)

"*My mum had been bringing me in cakes and that in..... my mum comes in everyday anyway. She'll ask if I want anything and bring stuff in.*" (Patient 2)

"*Every evening I went down to the restaurant.*" (Patient 4 wife)

"I went down and had my dinner down the stair (in the canteen). My sister got me dinner. It was good to get..... and the steak and chips were really nice." (Patient 14)

It was hypothesised that familiar food, habitual mealtimes and social eating were socio-cultural influences which facilitated the nutritional intake of post ICU patients.

However, in contrast to the benefits of family support in increasing oral intake, it was observed that family members could exert a negative effect on eating. Pressure from families to eat more, to put on more weight, to get better more quickly was found to be very stressful for patients and had a negative impact on their eating behaviours. The quote from a patient's wife illustrates this:

"I think we were all on top of him, everybody was 'you have to eat, you have to eat', you know the staff and family I suppose..... I think at that stage you were starting to get quite annoyed because it was all very well for us but if you cannae eat....."
(Patient 15 wife)

5.5.4 Organisational issues

There were also a number of organisational issues such as problems with hospital meals, service delivery issues and lack of staff awareness of nutritional issues which influenced patients' experiences of eating after critical illness. These are described in turn below.

5.5.4.1 Hospital Meals

5.5.4.1.1 Portion sizes

Hospital meals were found to influence nutritional intake. Patients often reported that initially they found the quantity of food on their plate off putting although they recognised that it was a lot less than they would normally eat. One patient said "*Well I asked for small, but it's a decent sized portion for me*" (Patient 15). Another patient commented "*I always tick off small amounts but I even have smaller than small amounts*" (Patient 5).

5.5.4.1.2 Ordering issues

Patients reported that they did not always get what they had ordered and this meant that they ended up not eating the meal as these quotes illustrate:

"Yesterday they dinnae even ask me and they gave me porridge and I dinnae like porridge." (Patient 2)

"They went and gave me fish pie and I dinnae like fish. They said I ordered it and I never ordered it..... I got telt to try and eat what's there." (Patient 7)

"*I asked for cheese pasta, cheese and pasta and they had brought mine out and I dinnae take vegetables ken what I mean so that was another meal I never ate.*" (Patient 17)

5.5.4.1.3 Food quality

Many patients commented on the poor quality of the food and felt that this adversely affected their intake. The quotes below describe the issues drawing on the examples of cold toast and tasteless chicken:

"*Well the toast is horrible. It's not their fault. I suppose by the time it comes up from the kitchen and gets to the ward it's like chewing plastic.*" (Patient 5)

"*The toast, it's like it was made about 5 hours before, ken it's like beer mats. Cause I love a bit of toast but all I ask, it's nothing ken Jamie Oliver or anything like that, just a bit of toast crisply done.*" (Patient 3)

"*(The toast) it's freezing. The toast's made yesterday I think. It's like rubber.*" (Patient 6)

"*The other day it was sweet and sour chicken. I thought I'll get that aye, I fancy that so I got it, there wisnae nae taste aff it. Nae sweet, nae sour, nae nothing. It was so bland and I thought oh my God, nup.*" (Patient 14)

5.5.4.1.4 Timing of meals

Some patients reported issues with structured mealtimes and the timing of hospital meals as this was very different to what they were used to at home. Patients highlighted they found the meal times very early and they were not ready to eat at this prescribed time. The quotes below illustrate these points:

"*You know this sort of breakfast, lunch, supper, I mean that's just not for me you know, I sort of ate when I felt like it. But this regimental..... well it's far too early for breakfast but I force myself you know. Getting a cooked thing stuck in front of your face at 12 o'clock midday, it's just a, it's a struggle.*" (Patient 5)

"(My wife goes to the canteen) and I have my main meal at 6ish so I pushed it back and I found that a lot better..... (hospital meals are) the wrong time, you know I can't get my head around that you have your main meal at 5 o'clock. Now I understand the reasons why, I'm not stupid, they can't base their meal regimen around me. But it is a main part, it has a big impact on me." (Patient 4)

5.5.5 Observations

Ward based observations revealed a number of factors that influenced nutritional intake in post ICU patients. These are described in more detail below.

5.5.5.1 Meal times

5.5.5.1.1 Missing mealtimes

It was observed that investigations or procedures sometimes coincided with mealtimes which meant that patients either missed their meal or if food had been left it was cold when they were eventually free to eat it. An exemplar observation is given below.

"The lunch tray is delivered and left on patient 17's table. The room is empty. 20 minutes later the tray is cleared away by a ward hostess. The patient has still not returned".

5.5.5.1.2 Assistance at mealtimes

Observations revealed the need for assistance at mealtimes and this was particularly evident in patients who were experiencing physical debilitation after critical illness including fatigue, muscle weakness and neuropathy. Patients struggled to open packaging e.g. butter, jam, orange juice and cheese and also with the physical act of eating. These problems with lack of assistance led to meals being left as the exemplar observation highlights.

"Breakfast tray is delivered by a ward hostess. The patient is lying in bed propped up on pillows. She tries to open the foil lid of the orange juice, it slips off the tray and falls onto the bed. A trail of rice krispies on the sheets illustrates her difficulty in manipulating the spoon from cereal bowl to mouth".

Post ICU patients are cared for on acute hospital wards and have different needs to a typical short stay medical or surgical patient. The researcher witnessed several conversations between nursing staff who were discussing patients in the study. Patients were described as '*too dependent*' and '*lazy*' as they required a high level of nursing care including assistance with feeding.

5.5.5.1.3 Social aspects of mealtimes

Observations highlighted the importance of social interaction at mealtimes and the benefits of this interaction in facilitating food consumption. Post ICU patients in four-bedded ward bays were observed chatting and laughing during mealtimes, in contrast patients in side rooms ate their meals in isolation.

5.5.5.2 Service delivery issues

Observations revealed that service delivery issues relating to the supply and consumption of oral nutritional supplements, snacks and enteral feeds affected nutritional intake. These problems are described in detail below.

5.5.5.2.1 Delivery of nutritional supplements

The system for delivery of nutritional supplements was observed to be problematic. The current system involves a number of steps, each of which needs to be carried out in order for the patient to receive the correct supplement. Firstly kitchen staff print off labels, the details of which are inputted by dietitians into a diets programme. The labels identify the type and quantity of supplements and should be stuck on the appropriate carton. Then they are delivered to the ward by ward hostesses who then put them in the pantry fridge.

In order for the supplements to be given to the patient they need to be prescribed on a kardex; however, this procedure differs across the hospital. In some wards a separate dietietic kardex is used and the supplements are prescribed by the dietitian on this. In other wards the supplements are written by the dietitian on the drug kardex. The problem with a second kardex means that it can easily be overlooked and if staff are busy it is seen as a lower priority compared to the drug kardex. Supplements may simply not be signed for on the kardex or may be coded as patient refused but due to decreased dietetic review this may go on for some time without being picked up and acted upon.

Observations also highlighted that the supplement may be signed for as given by the nursing staff but is not actually consumed by the patient. This occurred for a variety of reasons such as the patient simply disliked the supplement, the carton was not opened and the patient was unable to open the lid and pierce the silver top with a straw or the patient was sleeping and was not aware that the drink had arrived.

5.5.5.2.2 Delivery of snacks

A similar system operates for the administration of snacks and again it was noted that there are problems in getting these to the patients. In some wards these are documented on a separate dietetic kardex, in other wards a recommendation for 'snacks' was written by the dietitian in the medical notes. Patients frequently reported that they had to ask for their snack. One patient was isolated in a sideroom due to an infectious disease and he reported huge problems obtaining his snacks and

supplements as they were not brought in for him and he was unable to come out of his room to ask for them. Observations highlighted that the system relies on patients being able to ask for the snacks or supplements. Therefore anyone who is unable to do this, for example patients experiencing delirium or confusion, is less likely to receive their recommended snacks or supplements. The quotes below illustrate the problems patients experienced receiving their snacks:

"*..... they are not brought up. I forget about it. I forget to ask for them*"
(Patient 4)

"*I'm meant to be taking one a day..... but it's a case of you know you've got to ask the nurses and of course they are so busy doing..... if they remember to , you know you've got to keep saying are you remembering so they're probably thinking what a pain.*" (Patient 5)

"*The nurses are meant to give me something (supplement) but they never gave me it.*"
(Patient 14)

"*I've no had them (snacks) since Sunday 'cause they said, 'Have you had your cheese and crackers?' and I goes 'I'm wanting scone and jam.' They says, Right I'll go away and get you it' and never came back and I've no had any snacks since then.*"
(Patient 2)

"*I never got my scone this morning.*" (Patient 3)

"*(My scone) dinnae arrive yesterday.*" (Patient 9)

5.5.5.2.3 Delivery of enteral feeds

Another issue was related to enteral feeding as there were numerous instances observed when all of the prescribed feed was not administered. Observations revealed that tubes were inadvertently removed with subsequent delays in re-passing a new tube, feeding time was reduced due to a medical procedure e.g. scan, X-ray or operation, or there was a reduction in the volume of feed delivered as the feed rate was lowered or stopped due to the presence of gastrointestinal symptoms such as nausea, vomiting, bloating or diarrhoea. These reductions in feed volume were

unaccounted for and although this occurred on a regular basis, no subsequent increase in feed volume was documented.

5.5.5.3 Limited staff awareness of nutritional inadequacies

Observations revealed that there were a number of healthcare professionals influencing the delivery of nutritional care for the patient including medical staff, nurses and dietitians. Accounts relating to nutritional intake documented in the medical notes by doctors were found to differ vastly for the details of food intake given by the patient. Medical staff had written "*eating well*", "*good oral intake*", or "*eating and drinking well*" when information from food record charts showed that actual dietary intake was inadequate. This could be due to the fact that medical staff received an erroneous account of the patient's intake from the nursing staff, the patient was observed at one mealtime leading to an overall conclusion about intake or the patient had said that they were eating well. However, the concept of 'eating well' can mean vastly different things. For example it could mean that the patient was eating better than they had been before admission to hospital when they may have been acutely unwell and eating very little; they were eating better than the day before when they hardly ate anything or they were actually consuming sufficient quantities to meet their nutritional requirements.

The conflicting opinions about the adequacy of the patients' dietary intake was noted to affect on-going nutritional care. One patient had an overnight nasogastric feed and was eating during the day. A dietitian had recorded in the medical notes that oral intake was still insufficient to meet nutritional requirements and recommended continuing the supplementary enteral nutrition. A subsequent entry in the notes from the doctor stated that the patient was eating well and the nasogastric tube was to be removed. This reflects the hierarchical nature of decision making within the NHS where medical staff have limited nutritional knowledge compared to dietitians, yet current hierarchy means that the medical decisions take precedence. Dietitians are not routinely included in medical ward rounds or as part of an integrated clinical team which limits opportunities to highlight nutritional issues.

5.5.5.3.1 Dietetic Intervention

Dietitians were involved in the nutritional care of some of these patients. Observations revealed that six patients were not reviewed by a dietitian during their ward stay despite the fact that all patients were assessed by the critical care dietitian in ICU and therefore after discharge from ICU should have been reviewed by a ward dietitian.

Increasing financial pressures on the NHS have affected staffing levels and as a result dietitians, in line with all allied health professionals, have had to introduce a prioritisation system where patient referrals are categorised in order of priority. Patients who require artificial nutrition or those who are screened as malnourished have been allocated the highest priority codes.

Nutritional screening should have identified patients who required re-referral to dietetic services. Observations of ward practice revealed that nutritional screening was rarely carried out by ward staff therefore on-going nutritional problems would not have been identified.

5.6 Discharge from Hospital

Due to the acute nature of the hospital many of the patients in the study had a short ward stay despite the fact that some of them had a prolonged ICU stay. Over half of the patients were discharged home within a week of being transferred from ICU. Many of these patients did not feel ready to be discharged as these quotes illustrate:

"*Four days! I couldnae believe it myself when she told me I could go hame. I was actually happy like ken, thank fuck I'm going hame. But at the same time I knew I shouldnae have been going hame that early.*" (Patient 7)

"*Aye I felt I were ready but ken, just.....*" (Patient 3)

"*I wasnae positive 100% .....*" (Patient 16)

"*I wanted to go home but I wisnae ready.*" (Patient 17)

"*I always had the idea that I got chucked out rather quickly..... I thought I got bullied into it..... I could have done with another few days of just doing nothing you know..... sort of collect my thoughts together and so on, 'cause it had been a bit hairy the month before.*" (Patient 12)

Patient 12 used strong language to describe his feelings about being discharged from hospital. Words such as 'chucked out', 'bullied' and 'a bit hairy' highlighted the extent of his concerns.

5.6.1 Nutritional inadequacy on discharge from hospital

Twelve patients in the study were assessed by the researcher as having an inadequate nutritional intake at the time of hospital discharge. There are a number of criteria for discharge from hospital including being deemed medically stable and when "*physiological, social, functional, and psychological factors or indicators have been taken into account*" (DH 2004b p11). However, it is clear from the study that being 'nutritionally fit' is not one of the discharge criteria as many patients were discharged home with grossly inadequate nutritional intakes.

It is discharge from hospital that is perceived as the end of the patient journey by acute hospital staff and thus they are unaware of how the patient subsequently manages. For the researcher, as a clinical dietitian this project provided the opportunity to follow the patients' journey for three months after ICU discharge.

Two of the 17 patients in the study were initially transferred to another hospital for on-going rehabilitation. However, by three months post ICU discharge all patients were at home. Fourteen patients provided interviews at the three month time point. Of the remaining three, one declined further participation in the study, one had been readmitted to hospital with a severe stroke and the other had left the country to return to family overseas.

5.7 Transition from Hospital to Home

Patients experienced issues in their transition from hospital to home, including difficulties in adjusting to home life, challenges in everyday activities and fears and concerns. Each of these is described in turn below.

5.7.1 Difficulties in adjusting to home life

Interestingly, patients rarely mentioned eating when talking about their initial weeks at home. Their main focus was their ability, or lack of, to carry out other activities of daily living and their fears and concerns about how they, and their family, would cope with on-going issues.

Many patients highlighted how difficult they found the adjustment between hospital and home. One patient commented "*I don't know whether I was a bit too optimistic. I have found it harder than I thought I was going to. I have definitely found it harder*" (Patient 4). Another said "*It was harder because you weren't just lying in bed all the time with folk running after you*" (Patient 9). The challenges and concerns that patients expressed in facing their everyday activities are described in the section below.

5.7.2 Challenges in everyday activities

Patients described the challenges they faced just undertaking everyday tasks that they had previously taken for granted like walking up and down the stairs, getting in and out of the bath. One patient said "*Oh I couldnae get up the stairs and that for days. I actually went to stay with my mum for the first couple of days, slept on my mum's couch cause I couldnae bend doon and pick up anything and that*" (Patient 7). Another commented that "*It was difficult, I was just tired all the time and it was very hard going up and down the stairs*" (Patient 9). Another patient said" *It's a struggle going up the stairs initially..... I knew that it would take a while so I would rather get better here than in hospital*" (Patient 3). Yet another patient highlighted "*When I came hame at first it was hard, it was hard..... In there (hospital) you've got everything done for you, you've got yer meals made for you and all that and when you come home, yae've got to do all that yerself*" (Patient 14). Strong language was

used to describe the challenges and concerns that patients experienced such as 'difficult', 'hard' and 'struggle'.

5.7.3 Fears and concerns

Patients expressed a number of fears and concerns relating to their transition from hospital to home. Patients conveyed their concerns and fears about coming home from hospital and how they would cope at home as the following quotes illustrate. A male patient who lived alone said *"I knew I was coming back to look after myself and I knew I was a wee bit frightened of looking after myself, you know. I didn't know if I could manage the bath and things like that"* (Patient 16). Another patient commented "*You are away fae the protection sort of thing*" (Patient 3).

Some patients conveyed their anxieties about the impact their arrival home had had on family members and the burden it placed on them. One patient stated "*Well it put extra strain on my wife apart from anything else*" (Patient 9). A patient highlighted "*My wife is over 70 and she hadn't had time to make the house ready or anything like that*" (Patient 12). Another patient was aware that his limited mobility distressed his wife and said "*There is sometimes..... well (my wife) she gets sorta upset*" (Patient 3).

A few patients had been back in hospital since their initial discharge and expressed their concerns about their ongoing health problems. One patient described his experience as *"A blood clot appeared and my leg all swelled up. That was a week later (after discharge from hospital).....obviously I was worried about the blood clot that was in there, which it still is"* (Patient 2). A patient's wife said "*He's been back in (hospital) because he had a major bleed*" (Patient 10 wife). Another patient commented *"I was home for about two weeks then I was back in (hospital) for five weeks ..... My lung thingied up so I got a drain in"* (Patient 13).

Additionally many patients had been left with ongoing heath concerns as a result of their hospital stay. One patient said *"My daughter's paranoid about this MRSA, absolutely paranoid about it, like when the bairn comes up..... I've no even to*

touch the bairn..... and it's heartbreaking" (Patient 14). The use of strong language, using words such as 'heartbreaking' revealed the strength of the patient's feelings. Another patient mentioned *"My stomach, I don't think it has completely healed. The scar on the outside is feeling alright but I still feel tenderness inside so I think that'll maybe take a bit longer"* (Patient 16). Another patient stated *"The thing I would say is bloody oedema"* (Patient 4).

5.8 Nutritional Intake at Three Months Post ICU Discharge

When patients were asked about how they were eating at three months post ICU discharge, the majority felt that their intake had improved significantly since being discharged from hospital. Below are some quotes from patients that illustrate these improvements.

"(My eating is) better." (Patient 4)

"I don't have any problems eating." (Patient 9)

"Well since I came home I'm eating like a horse." (Patient 10)

"*(My eating is) on the whole not too bad.*" (Patient 11)

"*I think (eating) is back to normal.*" (Patient 13)

"(Eating is) a thousand times better, aye definitely....now I'm eating everything." (Patient 14)

"I'm just eating normal meals." (Patient 15)

Nutritional intake had improved by three months post ICU discharge. It was speculated that may be due to the fact that patients were at home thus alleviating a number of issues that had negatively influenced food intake in hospital. There were

a few patients who reported a poor nutritional intake at three months post ICU discharge. Below are some quotes from patients that describe this:

"I was eating quite well to start with but now I'm back to (drinking)." (Patient 2)

"(Eating is) sortie a wee bit better than what I was on the ward but nothing great." (Patient 3)

"I've been trying to have a stable diet and that but just sometimes I've no got an appetite and other times, other days I have." (Patient 6)

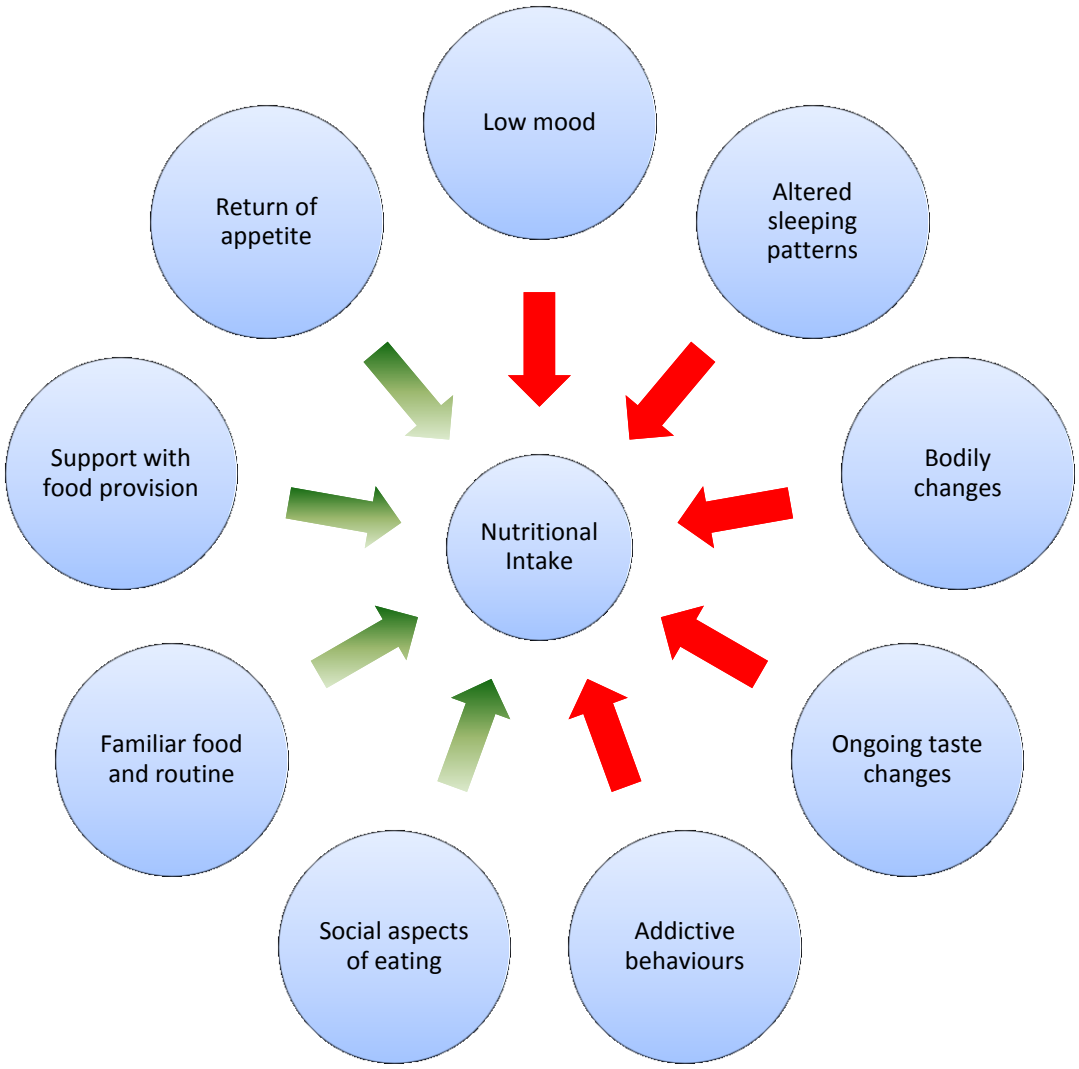
*"I'll no eat until my stomach's telling me I need something to eat..... I dinnae ken how many times she's cooked my dinner and I've left it like." (*Patient 7)

Three of these patients had a previous alcohol dependency and had started to drink again since discharge from hospital. The other patient was malnourished before admission to hospital and had a number of co-morbidities which affected his nutritional intake.

5.9 Factors Noted to Influence Nutritional Intake at Home

Through the process of constant comparison, there were a number of factors emerging from the data which were found to have either a positive or negative effect on nutritional intake. These factors are presented in Figure 12, the green arrow corresponds to a factor that had a positive effect on eating, the red arrow indicates factors that had a negative influence on food intake. Each of these factors are explored in more detail below.

Figure 12: Positive and negative factors influencing nutritional intake



5.9.1 Positive Influences on Nutritional Intake

The factors which had a positive influence on nutritional intake were: return of appetite; support with food provision; familiar food and routine and the social aspects of eating. Each of these is described in turn below.

5.9.1.1 Return of appetite - eating as a pleasure

At three months after ICU discharge many patients found that their appetite had returned or improved since discharge from hospital. This was associated with reports of eating being a pleasurable experience. The quotes below illustrate this:

"My appetite is good and I enjoy my food." (Patient 4)

"*I really enjoy what I'm eating."* (Patient 9)

"I enjoy eating." (Patient 15)

"I love nice things, nice fruits and things like that, nice meats, I do enjoy that." (Patient 17)

Conversely, there were a few patients who still struggled with a poor or variable appetite. For these patients eating was seen as a chore. The quotes below illustrate this:

"If you're no feeling like it (eating) and I know myself that I should be but it's one thing saying it and another thing daein it." (Patient 3)

"He's just no got the appetite. It doesnae matter what you try and kindae suggest or you ask him what he would like and then..... last week I had got quite a lot of things in and a lot of them was wasted." (Patient 3 wife)

"*I've been trying to have a stable diet and that..... sometimes I've no got an appetite and other times, other days I have.*" (Patient 6)

It was apparent that appetite was an important physiological factor in influencing food intake. Return of appetite was associated with improvements in nutritional intake with eating being viewed as a pleasurable experience. Conversely, lack of appetite reduced food intake and eating was perceived as a chore.

5.9.1.2 Support with food provision

Many patients had family members who cooked meals for them and some recognised the importance of this in ensuring a regular food intake. One patient said *"If it wasnae for my partner my diet would probably be how it used to be. I never used to eat nothing apart from last thing at night, whereas now I have my breakfast and that's made for me.....and my tea is always put down for me at the right time"*

(Patient 7). Another patient said *"I eat a lot more with my wife cooking for me..... if it wisnae being cooked for me I don't think I'd eat"* (Patient 17).

Those who lived alone had assistance from others for the provision of food. For some it was their children bringing meals to them. One elderly lady said *"My daughter does the cooking and brings it over when she comes"* (Patient 11). For another it was the support of her son who came to stay with her for a few months. She commented that *"He was very good and he did the washing.....and then he kept things moving in the house sort of thing, cups of tea every now and again"* (Patient 13). Another patient had her son in-law bring her round meals which she really appreciated. She said *"They were having tatties and he done the chops in gravy and it was turnip and brussel sprouts ay, so because they were having that they put some on a plate for me.....it was really good ay to get it made for you"* (Patient 14).

One young patient in her twenties who lived alone benefited from the help of a neighbour who cooked meals for her. She said *"I try to have a hot meal in the evening. My neighbour downstairs if I buy the ingredients, he'll cook it for me .....(my eating is better) when like it's getting made for me and that and I've just got to like heat it up and that" (Patient 6).* Another patient worked as a catering assistant and had meals provided for him at work. He highlighted that *"I get my meals at work and I don't need to cook..... I don't like cooking for myself to be honest"* (Patient 16).

Although this support in food provision had an advantageous effect on eating, it was clear that many patients were reliant on this and if their circumstances had changed it could have had a detrimental effect on their nutritional intake. The vulnerability of patients who lived alone was a recurring theme and highlighted the importance of support from family or friends.

5.9.1.3 Familiar food and routine

Familiar foods and eating habits were important in promoting nutritional intake. Patients described their enjoyment in having foods that they liked, prepared the way they wanted and served at preferred times. Below are some quotes which illustrate this:

"I suppose you get used to a certain type of food that you have at home and how it was done. I mean something like an egg, some people like it hard boiled and some soft and ken it's just your own habits." (Patient 3 wife)

"That was what I had when I first got home, a nice crispy toast and scrambled egg, lovely." (Patient 3)

"We eat what we like and that includes a fair spectrum." (Patient 10)

".....at home you feel you can do, you can eat when you want and if you feel like eating you know in-between, you know having a wee bit more often, small meals a bit more often." (Patient 15)

"I think that's cause it's home food you know and times as well.....you know I had said this to you before, that you know having my lunch at 12 o' clock and my dinner at 5.....I've had too many years of psyche where that hasn't applied, you couldn't just change that around." (Patient 4)

The quotes highlighted the importance of familiar food and eating patterns in relation to nutritional intake. There was a stark contrast between hospital food choices and timing of meals compared to eating at home.

5.9.1.4 Social aspects of eating

Another factor that influenced nutritional intake was the social aspect associated with eating. Some patients mentioned the enjoyment they derived from eating with others, usually their spouses, and the other aspects of meal times such as time with others and conversation. The quotes below illustrate this point:

"Eating with someone makes a difference because I like to yap, talk and talk." (Patient 12)

"I don't even know whether it is just having someone do it (cook) for you, I think it's just the fact there is more than one of you makes it better." (Patient 4)

"I think being alone you don't eat as well as if you've got somebody with you." (Patient 11)

These quotes illustrate the importance of companionship during mealtimes experienced by those living with family. Conversely, those who lived alone missed out on company and the social aspects of eating.

5.9.2 Negative Influences on Nutritional Intake

The factors which had a positive influence on nutritional intake were: low mood; bodily changes; on-going taste changes and addictive behaviours. Each of these is described in turn below.

5.9.2.1 Low mood

Patients commonly reported low mood, often associated with on-going health concerns, frustration with slow recovery or other factors such as social isolation resulting in loneliness and boredom. The quotes below illustrate this:

"*You say to yourself 'How did you manage to get pneumonia and things like that and how long will it be until you are a lot better?'..... ken you feel down a bit."* (Patient 3)

"I mean I was getting tablets for anti-depression, there is a difference between being fed up and being depressed. I mean I was a trained nurse so I know the difference. I was never clinically depressed." (Patient 15)

"I was a wee bit depressed..... slight depression but no much.....I prefer to be busy you know. It was terribly boring when I wisnae doing nothing." (Patient 16)

"You know the whole thing has picked on every other organ and so now it has picked on the biggest one (talking about his widespread dermatitis).....it does get you down." (Patient 4)

"*I'm fed up counting the bricks on that wall. There's only so many books you can read and day-time telly is crap.*" (Patient 9)

Interestingly, only one patient explicitly made the connection between low mood and reduced nutritional intake. She stated *"If I feel down I'm not particularly hungry"* (Patient 11).

5.9.2.2 Altered sleeping pattern

Changes to sleep patterns were mentioned by many patients with these changes persisting at three months after ICU discharge. A number of patients reported difficulty sleeping at night time, some had sought help from GP in the form of sleeping tablets because of the extent of the problem. Many patients would go for a sleep during the day and this meant that meals were often missed, noticeably breakfast or lunch. This reduction in waking hours during the day limits opportunities for food intake. This is illustrated in the quotes below:

"I was just having a couple of naps in the afternoon and I was sleeping all night. Some mornings I could hardly get up because I would be waking during the night." (Patient 13)

"He would not get up till maybe half past 12 ..... I would say breakfast has become lunch, because he has been getting up that bit later." (Patient 3 wife)

"My sleeping pattern has gone so I've been having a kip in the day..... sometimes I miss lunch." (Patient 4)

5.9.2.3 Experiencing bodily changes

Patients experienced a number of on-going bodily changes that influenced their nutritional intake after discharge from hospital. These included: taste changes; physical changes and changes to self and identity. Each issue is described in turn below.

5.9.2.3.1 On-going taste changes

A few patients experienced on-going problems with taste changes which affected their eating. The quotes below illustrate this:

"Taste is awful sometimes..... hot tea I take sweeteners in that and it tastes totally different..... but there is a lot of foods em, usually hot things. It's a sort of metallic kind of taste, a funny taste." (Patient 12)

"He's also had this aftertaste in his mouth again that he had when he first came out of the hospital." (Patient 3 wife)

5.9.2.3 2 Physical changes

Patients described on-going physical changes to their body at three months post ICU discharge and continued to experience problems with fatigue, weakness and fluctuating energy levels. Interview data highlighted that these bodily changes had a direct effect on nutritional intake as the quotes below illustrate.

My worst thing at the minute is weakness and tiredness and of course my appetite. But I think that having them both that's bound to stem onto your appetite." (Patient 15)

"He went out but I think that's cause everybody's saying to him you know you need to get up and get yourself out a bit..... We attempted to go to Costco to get a book and then we went and got a nice bit of fish..... By the time we got back he just felt that weak he never had his tea at all." (Patient 3 wife)

5.9.2.3.3 Changes to self and identity

These ongoing physical limitations meant that patients were reliant on others to help them, usually family members. This again draws attention to the vulnerability of patients who lived alone as they had no one to rely on. For some patients assistance was required to get out of the house, for others it was help simply to be able to carry out the activities of daily living. The interview data revealed that the changes to the physical body also affected how patients saw themselves and the way others perceived them. One patient said *"I was just tired, I was tired. If there was a cup of water sitting on the table, instead of going and getting that cup of water I would ask somebody to do it for me. I find it all really strange because that's just not me."* (Patient 17). Patients had to develop strategies to cope with their limitations; one patient described how he had altered his daily routine to accommodate his restricted physical abilities. He said "*Trying to get her (partner) out of bed is impossible and I*

was needing her to dae things for me at the start in the morning but now I've got into a routine, get all my tablets ready before I go to bed and that" (Patient 2). There was a lack of understanding from family and friends about the extent of physical disability after critical illness and the timescales involved in the recovery process. It was apparent that some patients felt pressurised by family or friends to re-engage with their usual activities.

Patients were also profoundly affected by their ICU experience and many were still coming to terms with all that had happened to them. Their experiences meant that many patients re-evaluated themselves and their lives. The quotes below illustrate this:

"Em, appreciating things more and stuff like that. Just general things that normally you take for granted." (Patient 6)

"..... in a way it's made me look at the whole of life a bit more differently so I suppose food comes into it quite a lot..... I think I appreciate food a bit more now." (Patient 12)

5.9.2.4 Addictive Behaviours

There were three patients who had a documented dependency to alcohol and drugs prior to admission to ICU. All patients had regressed to their addictive behaviours at three months post ICU follow up. One patient did not admit her return to drinking however had been readmitted to hospital with a fall due her intoxicated state. The alcohol and drug excess had a detrimental effect on these patients' nutritional intake. This is illustrated in the quotes below:

"I was eating quite well to start with but now I'm back to drinking, I ken I'd still be drinking anyway..... it didnae last. Back smoking. That took a couple of weeks before, 'cause I had a fag the first time I came out and that was disgusting so I just thought nup I'm no gonna smoke but I ended up smoking eventually." (Patient 2)

"If I've been out drinking I cannae really be bothered (to eat)." (Patient 7)

Another patient's wife highlighted her perceptions about the effects of addictions on nutritional intake. She said "*Poor diet, they are just going back to that. If they have no got a lot of money and they would prefer to spend their money on whatever rather than a half decent meal, they are no gonnae get, I mean they have been helped out in the hospital but they have got the rest of their life..... and well we always say you are what you eat*" (Patient 3 wife).

Addictive behaviours had a negative impact on eating as food was replaced by the addictive substance. These patients often had chaotic lifestyles with irregular eating patterns. The effects of a chaotic life style were compounded in those who lived alone as no one was around to provide food or ensure that it was consumed.

5.9.3 Other Factors Influencing Nutritional Intake

There were a number of other factors that influenced nutritional intake. These included: changing food preferences; healthy eating messages; and the need for dietetic advice. Each of these is discussed in turn below.

5.9.3.1 Changing food preferences

Changes in food preferences were noted by patient's spouses since coming home from hospital. These were highlighted by the spouse as they had become the caregivers and had taken on the responsibility for food provision. Some patients had developed an aversion to food that they had previously enjoyed and incorporated new foods into their diet were not previously consumed. The quotes below illustrate this:

"You've went off the milk lately. You've gone off the milk and having diluting juice." (Patient 15 wife)

"He's right off sauce, bottles of sauce." (Patient 3 wife)

"You've gone off coffee a bit at the moment." (Patient 4 wife)

"I certainly think you developed a sweet tooth..... like I would never have known him to suck on sweet shop sweets which he quite likes now and chocolate.....
(Patient 4 wife)

Changes in food preferences was observed to create some tension between the patient and family members. When previously enjoyed food was rejected by the patient it was particularly difficult for their relative. It was speculated that food was being prepared as a gift and rejection of the gift was also seen as rejection of the gift giver. Changing food preferences was another change for family members to come to terms with.

5.9.3.2 Healthy eating messages

Some patients reported that they were trying to eat healthily which is the message that has been heavily promoted in our society, the quotes below illustrate this:

"*I always make sure I have something healthy for tea.*" (Patient 2)

"*I suppose we've been trying to eat fairly healthily.*" (Patient 12)

"*It's a fairly balanced diet, maybe not enough vegetables but I make up for it in fruits and things like that.*" (Patient 10)

There was a tension between societal messages promoting healthy eating and the increase in calories needed for patients recovering from a critical illness. Some patients, especially those who had been overweight prior to their hospital stay, reduced their calorie intake in line with healthy eating advice. These patients expressed a desire to continue with the weight loss they had experienced as a result of their critical illness.

5.9.3.3 Need for dietetic advice

None of the patients in the study had seen a dietitian since discharge from hospital even though six of them had been advised to continue taking nutritional supplement drinks at home and these had been prescribed by the patient's GP. Patients were not

following the recommendations from the hospital dietitian with some taking fewer nutritional supplement drinks than advised and others were not clear how many they should be consuming. The quotes below illustrate this:

"No I just take it (supplement) sometimes." (Patient 14)

"He's no been taking them (supplement drinks)." (Patient 3 wife)

"*We were doing two (supplement drinks) a day and we dropped off to one a day.*" (Patient 4 wife)

"*I take it (supplement drink) sometimes.*" (Patient 14)

"*No as regular as I should be but I still take it (supplement).*" (Patient 15)

"*I think it's two I'm meant to have a day. Sometimes I take three or four.*" (Patient 6)

Some of the patients asked the researcher, whom they knew to be a clinical dietitian, for advice about their nutritional intake. The advice sought included information about foods high in protein, reassurance about the adequacy of dietary intake and questions regarding the number of supplements that should be consumed. The researcher also felt a professional responsibility to give advice to a few of the patients who were struggling nutritionally.

5.10 Summary of Chapter

This chapter explored patients' experiences of eating during the first three months after ICU discharge. It highlighted the wide range of factors that influence nutrition at different stages of the patients' journey: after transfer from ICU, during ward based care and after discharge from hospital. These preliminary findings revealed a number of themes that emerged from the data. The emerging themes were: the impact of the organisation on nutritional care; experiencing bodily changes and socio-cultural influences on eating.

The next chapter describes the quantitative results which are subsequently interpreted in light of qualitative findings from this chapter.

Chapter 6: Findings from Complementarity Mixed Method Analysis

6.1 Overview of chapter

This chapter will describe the emerging themes from an inductive analysis of the quantitative data, consistent with a grounded theory approach. Using the quantitative data the patients were classified into two groups; those who were well nourished or malnourished on discharge from ICU and remained in the same category at three months post ICU discharge. The findings from these groups were then explored using the quantitative data. The deviant cases, i.e. those who changed from malnourished to well-nourished or vice versa during the three month study period were then examined to elicit any potential nutritional differences. The patients were then divided into their RECOVER treatment groups to examine the impact of changing ward care. The findings were again explored using the quantitative data. Finally, in line with the complementarity mixed method approach, the quantitative results were interpreted in light of the emerging key themes from the qualitative analysis and any unexpected findings were discussed.

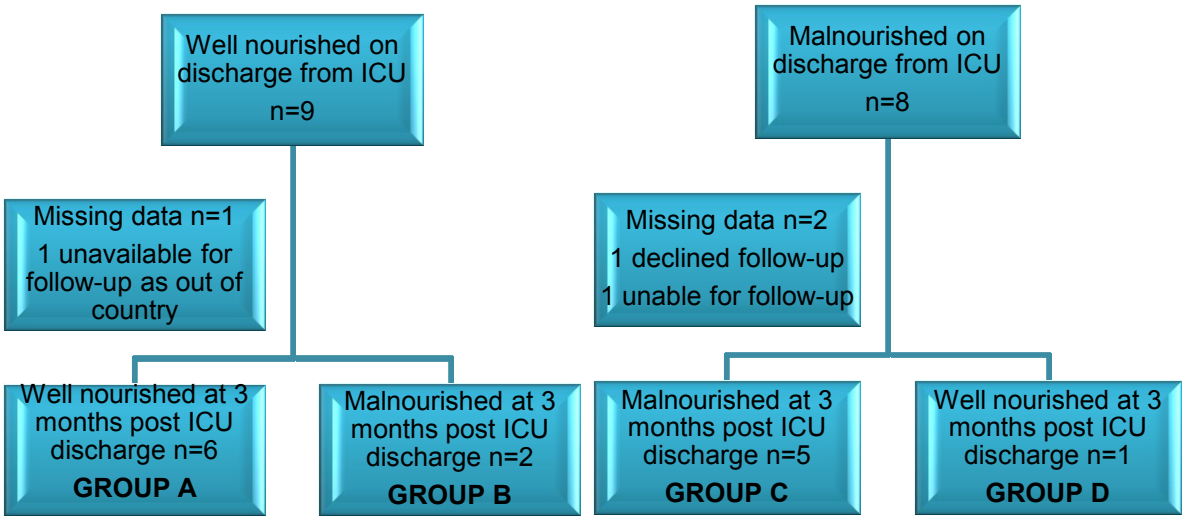
6.2 Comparison of well-nourished versus malnourished patients

On discharge from ICU to the ward the 17 patients were categorised into two groups using the Subjective Global Assessment (SGA) screening tool. Nine patients were classified as well-nourished and 8 were classified as malnourished (figure 11).

At three months post ICU discharge 14 patients were followed up. Of the remaining three, one declined further participation in the study, one had been readmitted to hospital with a severe stroke and the other had left the country to return to family overseas. The 14 patients were again assessed nutritionally using the Subjective Global Assessment screening tool and classified as either well-nourished or malnourished. Patients' nutritional status at three months was compared to their nutritional status at discharge from ICU.

Of the well-nourished on discharge from ICU group, 6 patients remained well-nourished at three months post ICU discharge and 2 patients had become malnourished by three months post ICU discharge. From the patients who were malnourished on discharge from ICU, 5 remained malnourished at three months post ICU discharge and 1 patient was shown to be well nourished at three months post ICU discharge (figure 13). For the purpose of description and analysis, these patients were categorised into four groups A, B, C and D, respectively.

Figure 13: Flow diagram



This demonstrated that the majority of the patients did not change groups over the three month period and remained either well-nourished or malnourished respectively. Only two patients went from being well nourished on discharge from ICU to the ward to malnourished at three months and one patient went from being malnourished on discharge from ICU to well-nourished at three months.

6.2.1 Patient Characteristics

The characteristics of all patients included in the study and the characteristics of the four sub-group analysis are displayed in table 12.

Table 12: Demographic details of patients

	Median (IQR)				
	All Patients n=17	**Group A** n=6	**Group B** n=2	**Group C** n=5	**Group D** n=1
Age (years)	55 (46-68.5)	55 (41.25-70)	42.5 (31-54)	68 (59-81)	52
Apache II*	18 (14.5-25)	18 (10.75-18)	28.5 (27-30)	18 (14-23.5)	18
Length of ventilation (days)	19 (5-33)	21.5 (5.25-34.25)	25 (9-41)	6 (3.5-20)	23
Length of ward stay (days)	10 (6-25.5)	8 (4-17.5)	20 (7-33)	8 (6.5-38)	14

*Apache II (Acute Physiology and Chronic Health Evaluation II) is a severity-of-disease classification system used in ICU (Knaus et al 1985). A score from 0 to 71 is calculated based on several measurements; higher scores correspond to more severe disease and a higher risk of death.

It is of interest to note that the patients in group C tended to be older and had less ventilation days than those in group A, although the length of ward stay was similar in both groups.

As the numbers in groups B and D are small, the results for these patients will be described later in this chapter. The next sections will focus on the results from groups A and C, those patients who remained well-nourished at 3 months and those who remained malnourished at three months, respectively.

6.3 Group A and C analysis

6.3.1 Nutritional intake

The nutritional intake of each patient was assessed on transfer from ICU to the ward and weekly thereafter during their stay on the ward. The mean for each patient's calorie and protein intake as a percentage of their nutritional requirements was calculated for the duration of their ward stay. Table 13 summarises protein and calorie intakes as a percentage of nutritional requirements across the two groups.

Table 13: Calorie and Protein Intake as a % of Nutritional Requirements During Ward Stay

	Group A n=6		**Group C** n=5	
Ward Stay	Median (IQR)	Min Max	Median (IQR)	Min Max
Mean calorie intake (% of req)	62.5 (34.5-101.5)	33 124	77.25 (53.5-91.75)	48 96
Mean protein intake (% of req)	55.38 (33.0-78.44)	18 82.75	73.25 51.75-96.35)	33 109.71

The results indicate that across both the groups patients were not meeting their nutritional requirements i.e. not achieving 100% of their calorie and protein requirements which would be necessary to maintain their weight. The median value was actually higher in group C, however, two of these patients received enteral feeding in addition to oral intake therefore this significantly increased their overall calorie and protein intake. Figures 14 and 15 show the mean calorie and protein intakes as a percentage of nutritional requirements during the patients' ward stay across the two groups.

Figure 14: Group A and Group C Mean Calorie Intake as a % of Nutritional Requirements During Ward Stay

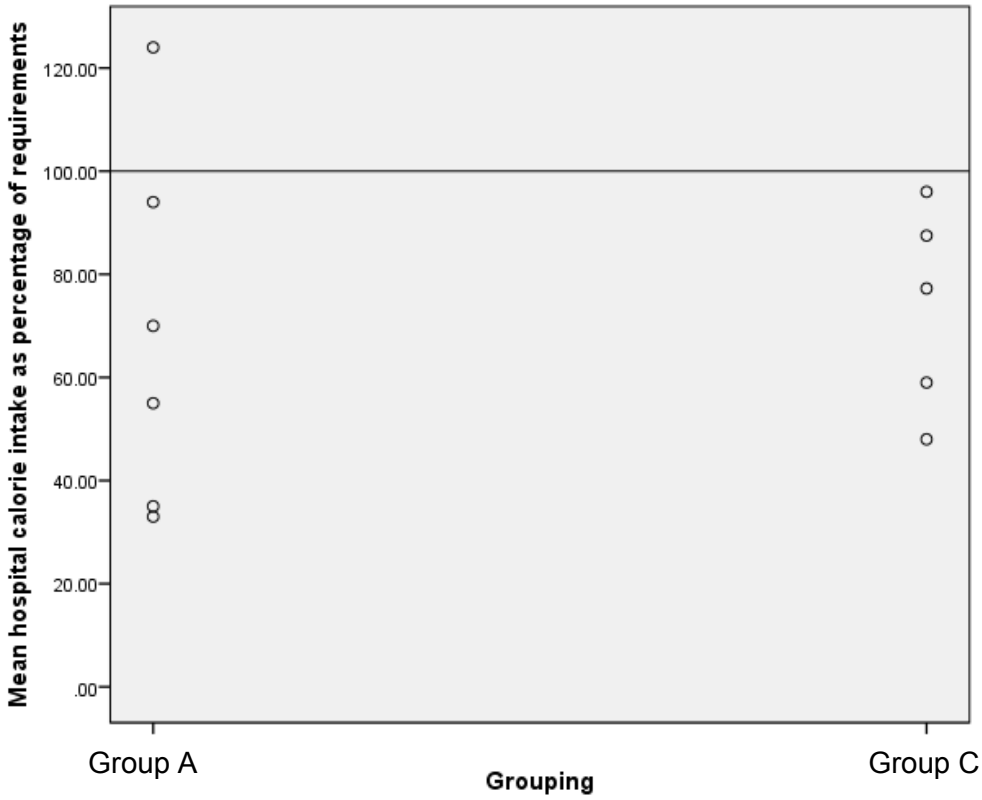
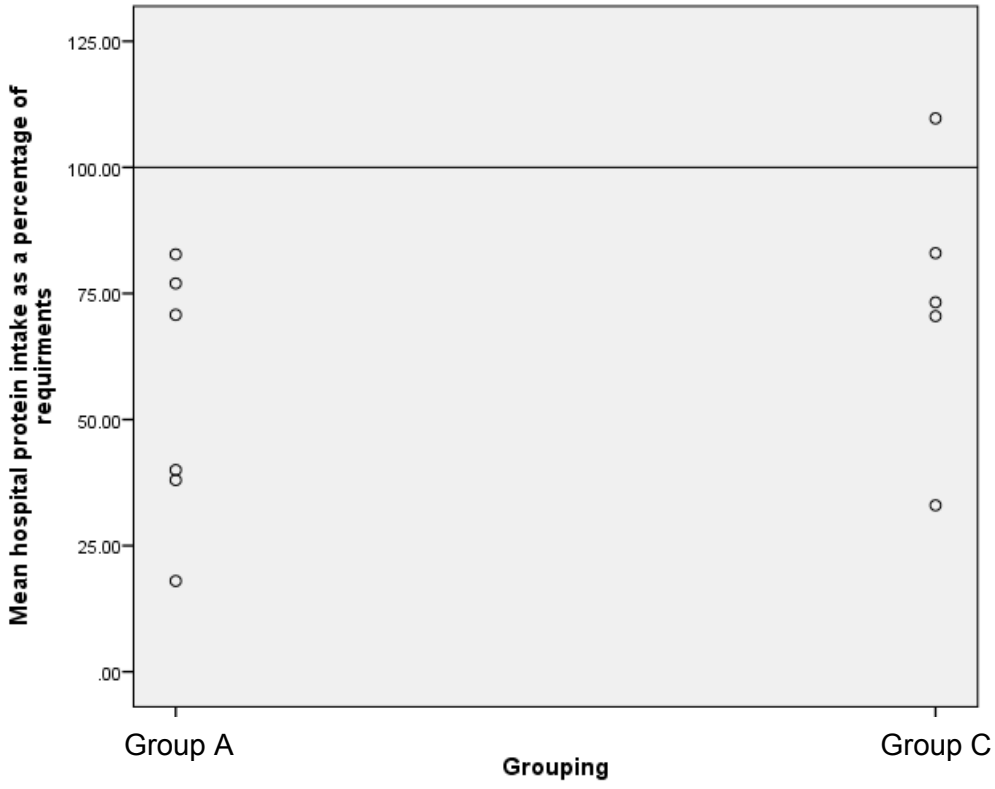


Figure: 15 Group A and Group C Mean Protein Intake as a % of Nutritional Requirements During Ward Stay



Calorie and protein intakes as a percentage of nutritional requirements were then compared across the two groups at three months post ICU discharge. The results are presented in table 14.

Table 14: Calorie and Protein Intake as a % of Nutritional Requirements at 3 Months Post ICU discharge

	Group A n=6		**Group C** n=5	
3 months post ICU discharge	Median (IQR)	Min Max	Median (IQR)	Min Max
Mean calorie intake (% of req)	87 (69.5-91.29	65 101	94 (69-106)	52 116
Mean protein intake (% of req)	76.5 (63.25-90.5)	49 107	79 (69.5-102.5)	63 108

At three months groups A and C were achieving similar calorie and protein intakes in relation to their nutritional requirements.

Individual calorie and protein intakes as a percentage of nutritional requirements within the two groups on transfer from ICU to the ward (baseline) to three months post ICU discharge are presented in figures 16 to 19. It should be noted that 100% of requirements would need to be achieved to maintain weight.

Figure 16: Group A Calorie Intake as a Percentage of Requirements

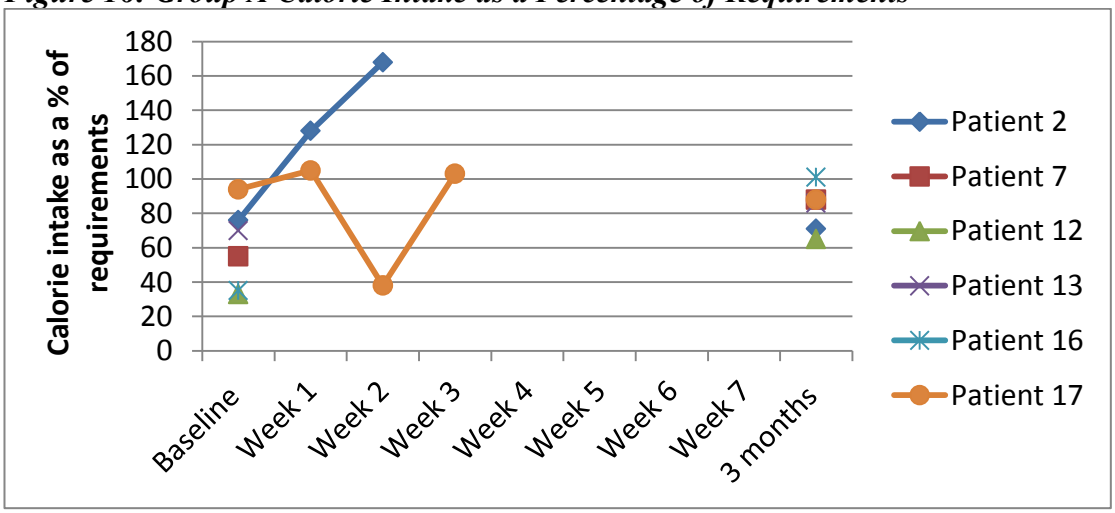


Figure 17: Group C Calorie Intake as a Percentage of Requirements

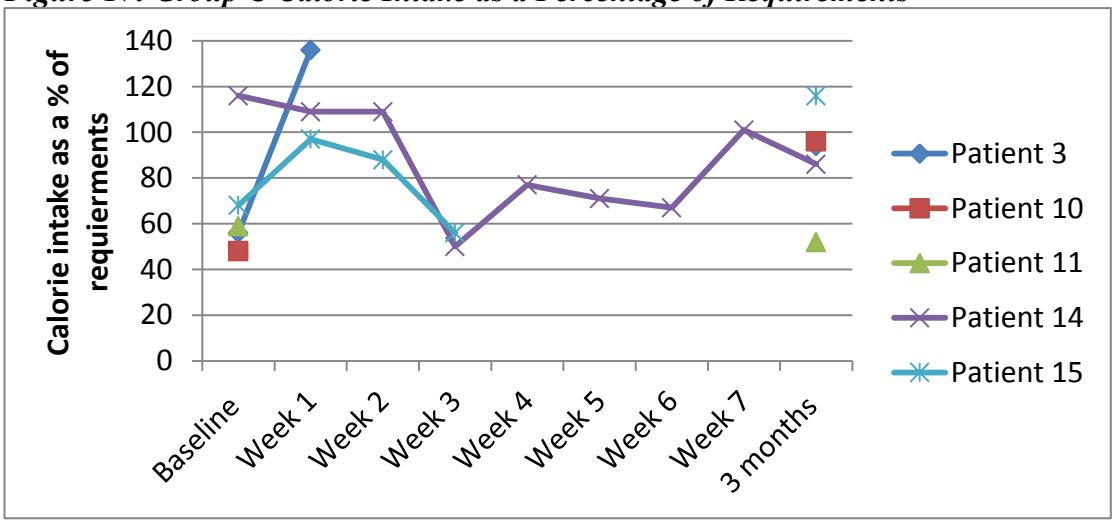


Figure 18: Group A Protein Intake as a Percentage of Requirements

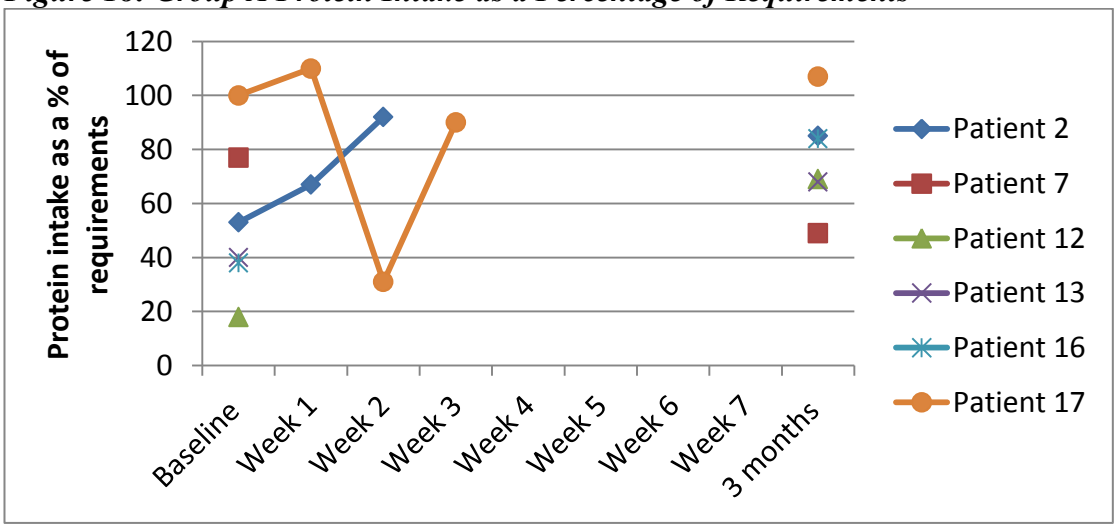
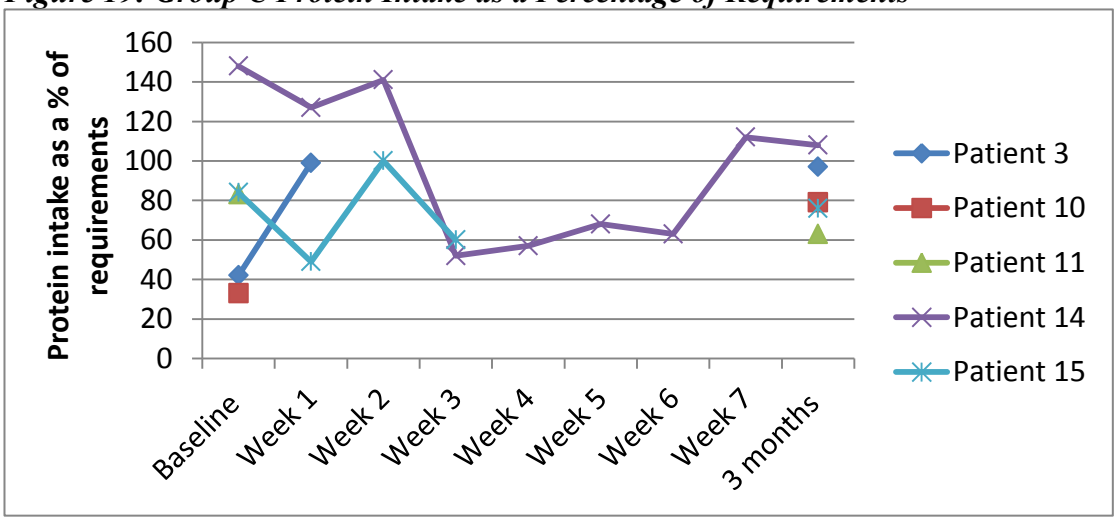


Figure 19: Group C Protein Intake as a Percentage of Requirements



From the graphs it is clear that many patients struggle to meet their calorie and protein requirements during their ward stay. This is particularly apparent during the first few days of admission to the ward.

Additionally the mean calorie and protein intakes as a percentage of nutritional requirements prior to hospital discharge were compared with mean calorie and protein intakes as a percentage of nutritional requirements during overall ward stay (figure 20 and 21). Two out of the 6 patients in group A and two out of the five patients in group C achieved 100% of their calorie requirements on discharge from hospital. None of the patients in group A and one from group C met 100% of their protein requirements on discharge from hospital.

Figure 20: Mean calorie and protein intake as a percentage of requirements during ward stay

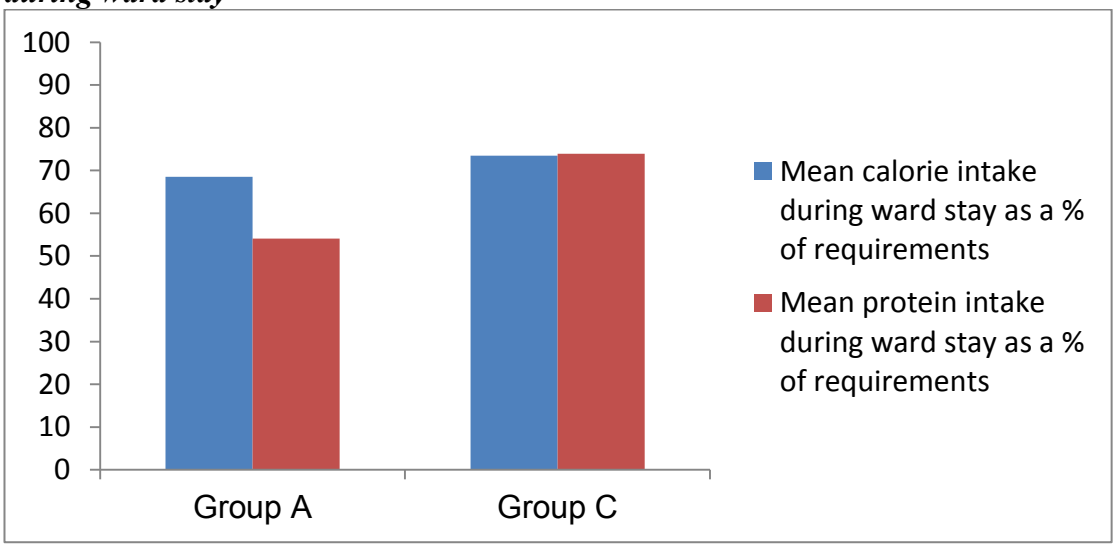
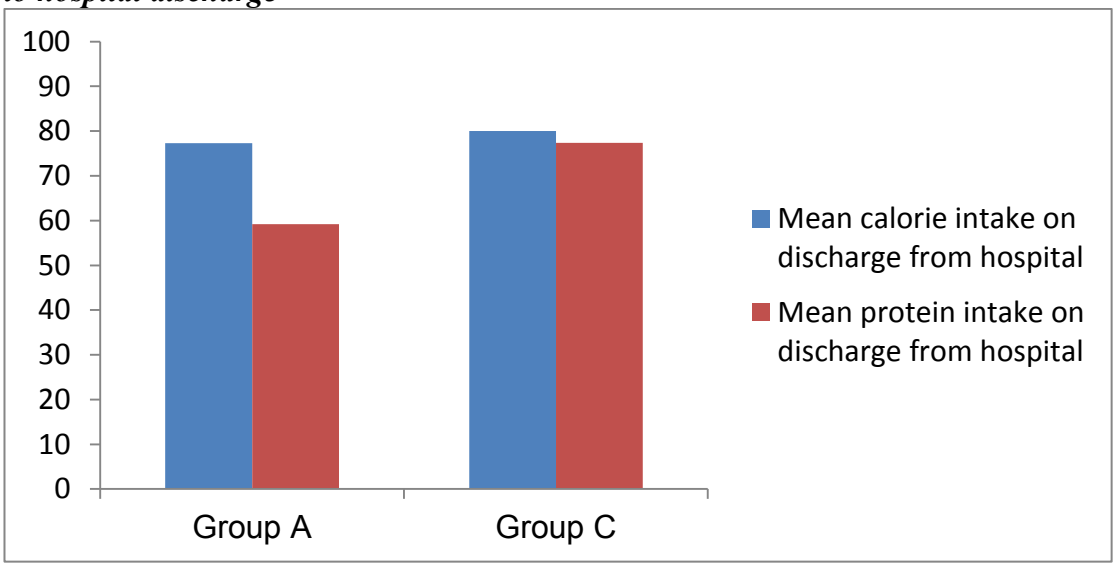


Figure 21: Mean calorie and protein intake as a percentage of requirements prior to hospital discharge



6.3.2 Visual Analogue Scales

Visual analogue scales (VAS) for breathlessness, appetite, pain and fatigue were measured on transfer to the ward and weekly thereafter during their ward stay. The scales range from 0 to 10 with 0 being no breathlessness, appetite, pain or fatigue to 10 which is the worst breathlessness, best appetite, worst pain and worst fatigue. As described previously, the mean for each patient's VAS was calculated for the duration of their ward stay. Table 15 summarises the VAS scores across the two groups.

Table 15: Mean VAS Scores During Ward Stay

	Group A n=6		**Group C** n=5	
Ward Stay	Median (IQR)	Min Max	Median (IQR)	Min Max
Mean VAS Breathlessness	3.5 (1.99-5.97)	2.4 8.2	2.2 (1.31-4.9)	0.8 6.1
Mean VAS Appetite	5.65 2.4-7.6)	2.4 7.6	3.37 (1.35-7.35)	0.6 8.5
Mean VAS Pain	4.9 (0.72-8.45)	0.17 8.45	1.75 (0.8-4.33)	0 6.26
Mean VAS Fatigue	7.53 (5.02-8.92)	3.3 9.3	5.2 (4.93-7.72)	4.7 8.5

Group A showed a trend towards worse breathlessness, pain and fatigue than group C during their ward stay. The appetite scores suggest that group C had poorer appetites than group A.

The VAS scores were then compared between the two groups at three months post ICU discharge. The results are presented in table 16.

Table 16: Mean VAS Scores at 3 Months Post ICU Discharge

	Group A n=6		**Group C** n=5	
3 months post ICU discharge	Median (IQR)	Min Max	Median (IQR)	Min Max
VAS Breathlessness	5.5 (2.42-7.17)	0.7 7.4	1.4 (0.85-2.1)	0.8 2.4
VAS Appetite	4.0 (2.22-7.2)	2 9	7.4 (2.8-8.65)	1.5 8.9
VAS Pain	3.1 (0-4.97)	0 5.2	2.3 (1.05-5.65)	0.9 6.2
VAS Fatigue	6.15 (4.35-7.8)	4.2 7.8	4.7 (2.85-7.5)	1.3 8.8

Overall scores for fatigue decreased in groups A and C from the ward to three months post ICU discharge indicating that patients were experiencing less fatigue. Median breathlessness scores increased in Group A at three months compared to ward measurements, however it was actually lower in group C at three months compared to ward results. Interestingly appetite scores improved in group C from the ward scores but the results from group A suggested that appetite was decreased at three months when compared to the ward scores. Individual VAS for breathlessness, appetite, pain and fatigue within the two groups from transfer from ICU to three months post ICU discharge are presented in figures 22 to 29.

Figure 22: Group A Breathlessness Visual Analogue Scale

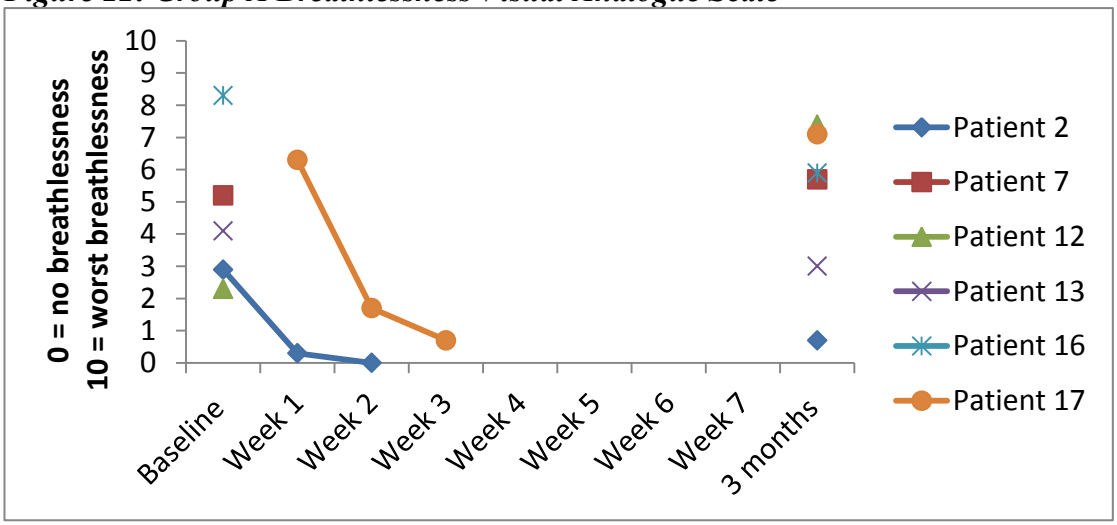


Figure 23: Group C Breathlessness Visual Analogue Scale

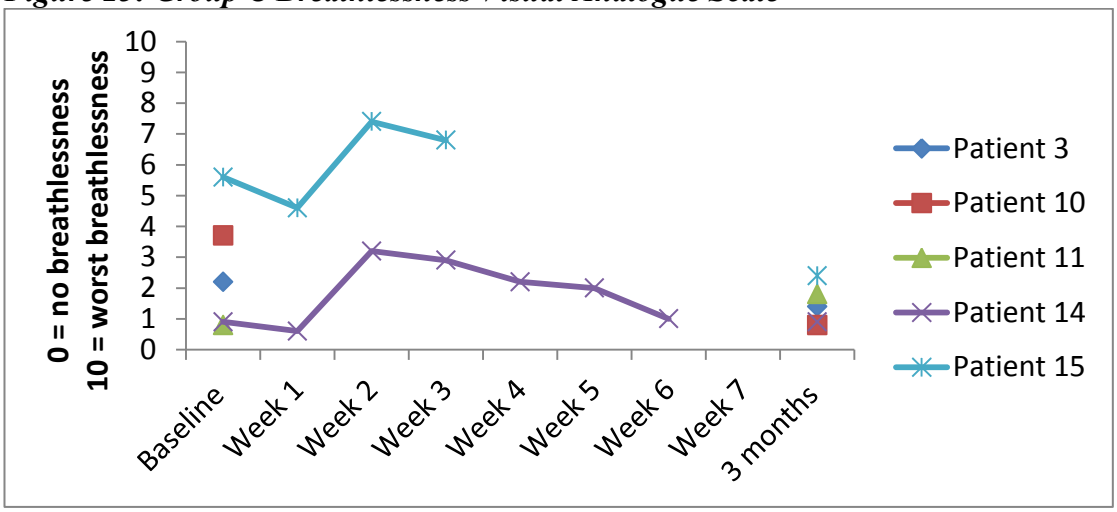


Figure 24: Group A Appetite Visual Analogue Scale

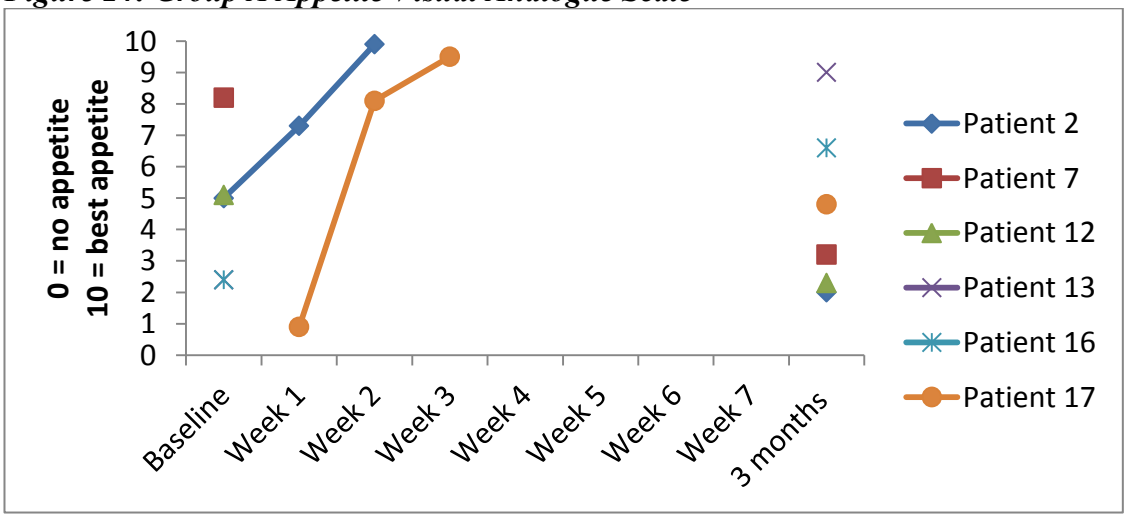


Figure 25: Group C Appetite Visual Analogue Scale

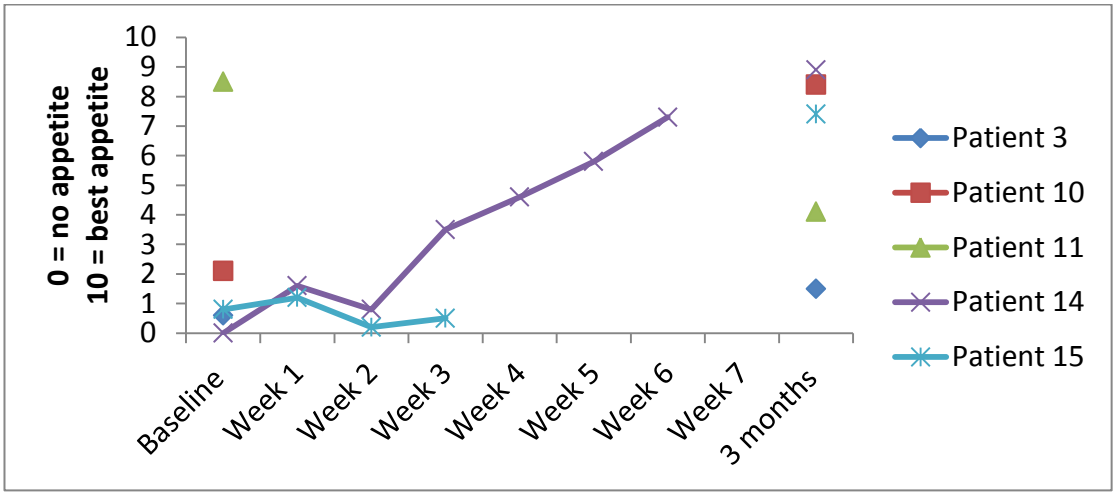


Figure 26: Group A Pain Visual Analogue Scale

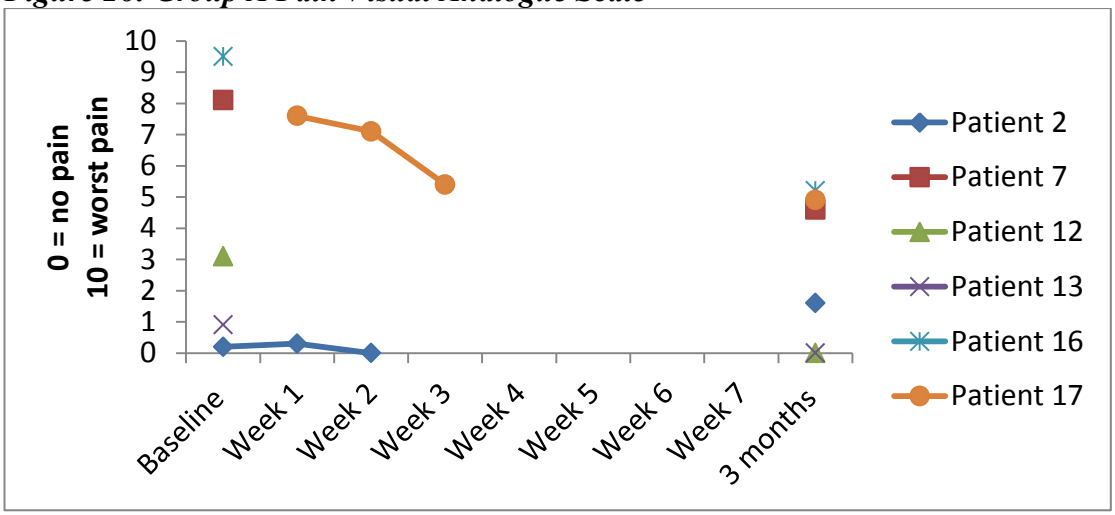


Figure 27: Group C Pain Visual Analogue Scale

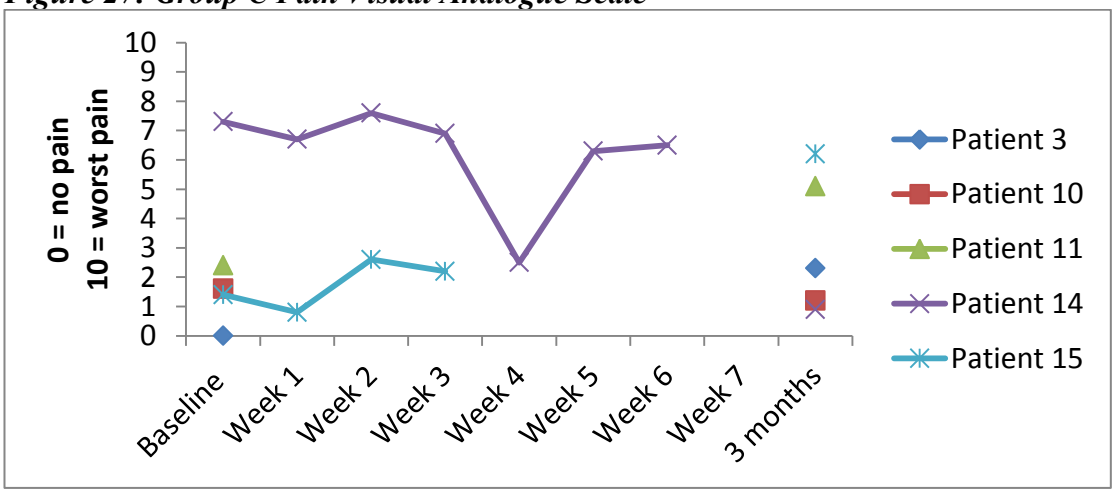


Figure 28: Group A Fatigue Visual Analogue Scale

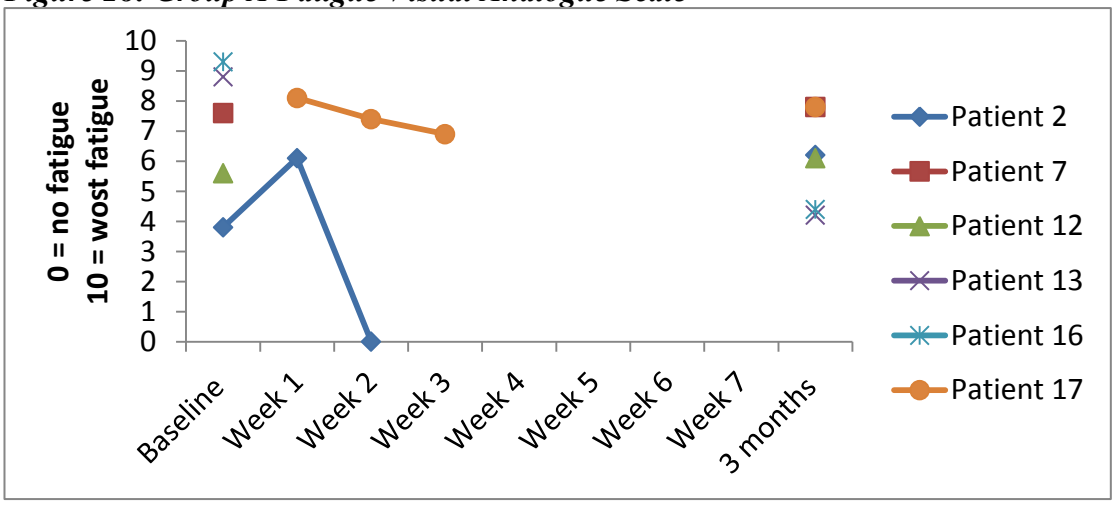
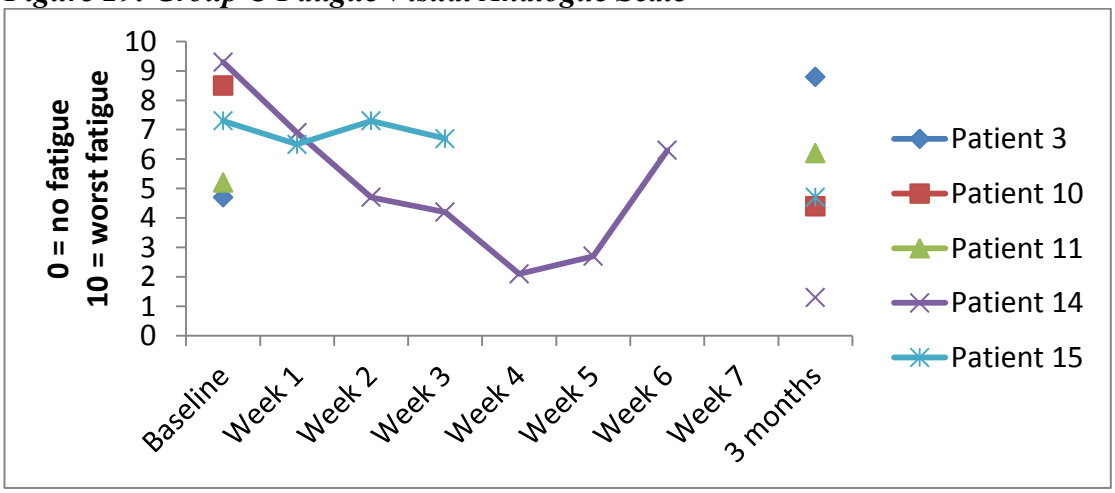


Figure 29: Group C Fatigue Visual Analogue Scale



6.4 Deviant group analysis

6.4.1 Group B

Group B consisted of two patients, both of whom were well nourished on discharge from ICU and at three months post ICU discharge were classified as malnourished using the Subjective Global Assessment tool.

6.4 1.1 Nutritional Intake

The results, similar to groups A and C, suggested group B also failed to meet nutritional requirements in hospital (table 17). Calorie and protein intakes had

improved by three months post ICU discharge, however nutritional targets were still not achieved (table 18). Data were only available for one patient at three months as the other, patient 6, was unable to give a detailed dietary history. This patient had a previously documented alcohol dependency and had started to drink heavily again on discharge from hospital. At the three month follow-up visit she smelled strongly of alcohol and her answers were very vague.

The data for group B is counter-intuitive as the patients' nutritional status deteriorated over the three month period yet their nutritional intake was greater at three months compared to ward stay. However, at the three months follow up calorie and protein intakes were still inadequate to maintain weight.

Table 17: Calorie and Protein Intake as a % of Nutritional Requirements During Ward Stay

	Group B n=2	
Ward Stay	Patient 4	Patient 6
Mean calorie intake (% of req)	29.5	91
Mean protein intake (% of req)	32.5	58

Table 18: Calorie and Protein Intake as a % of Nutritional Requirements at 3 Months Post ICU discharge

	Group B n=2	
3 months post ICU discharge	Patient 4	Patient 6
Mean calorie intake (% of req)	91	Missing data
Mean protein intake (% of req)	75	Missing data

Individual calorie and protein intakes as a percentage of nutritional requirements in group B are presented in figures 30 and 31.

Figure 30: Group B Calorie Intake as a Percentage of Requirements

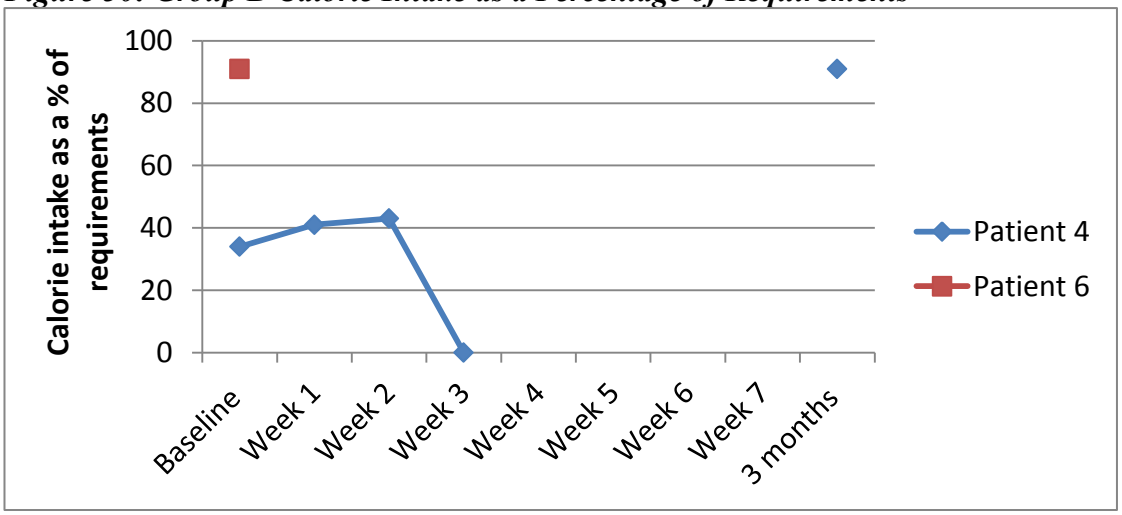
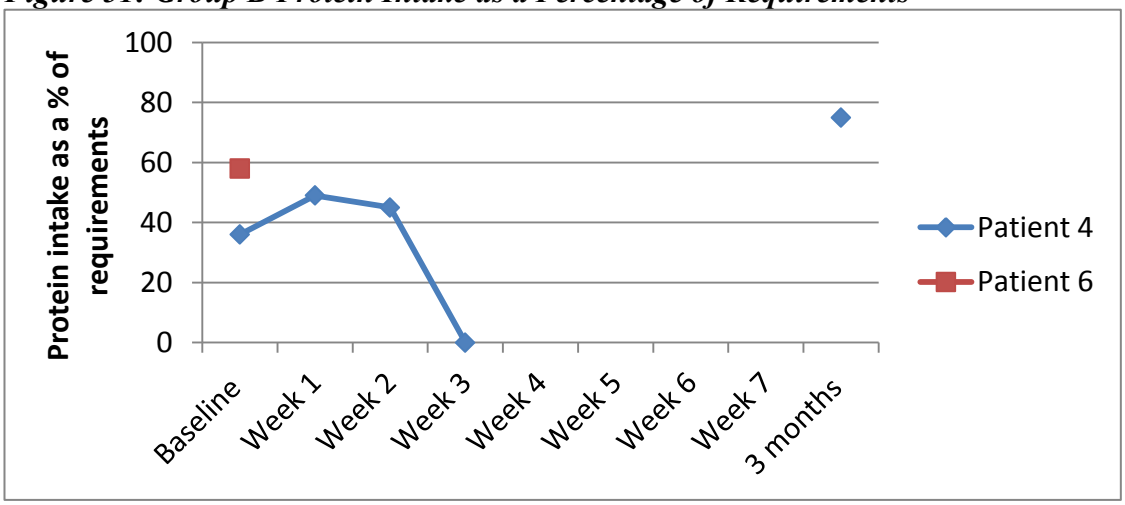


Figure 31: Group B Protein Intake as a Percentage of Requirements



6.4.1.2 Visual Analogue Scales

As described previously, the median value for each patient's VAS was calculated for the duration of their ward stay. Table 19 summarises the ward scores for VAS in group B.

Table 19: Mean VAS Scores During Ward Stay

	Group B n=2	
Ward Stay	Patient 4	Patient 6
Mean VAS Breathlessness	3.13	1.2
Mean VAS Appetite	6.83	3.3
Mean VAS Pain	4.07	1.0
Mean VAS Fatigue	5.4	0.0

Although group B had small numbers, the results suggested a lower reported prevalence of breathlessness and fatigue during ward stay compared with groups A and C.

The results of the VAS scores at 3 months post ICU discharge for group B are presented in table 20.

Table 20: VAS Scores at 3 Months Post ICU Discharge

	Group B n=2	
3 months post ICU discharge	Patient 4	Patient 6
VAS Breathlessness	5.4	5.7
VAS Appetite	9.9	7.1
VAS Pain	0.8	6.1
VAS Fatigue	7.1	6.4

The results suggest that the patients experienced more breathlessness, pain and fatigue at three months than during their hospital stay yet their appetite scores were better at three months, despite the fact they had gone from being well nourished at discharge from ICU to malnourished at three months post ICU discharge.

Individual VAS for breathlessness, appetite, pain and fatigue for group B from transfer from ICU to three months post ICU discharge are presented in figures 32 to 35.

Figure 32: Group B Breathlessness Visual Analogue Scale

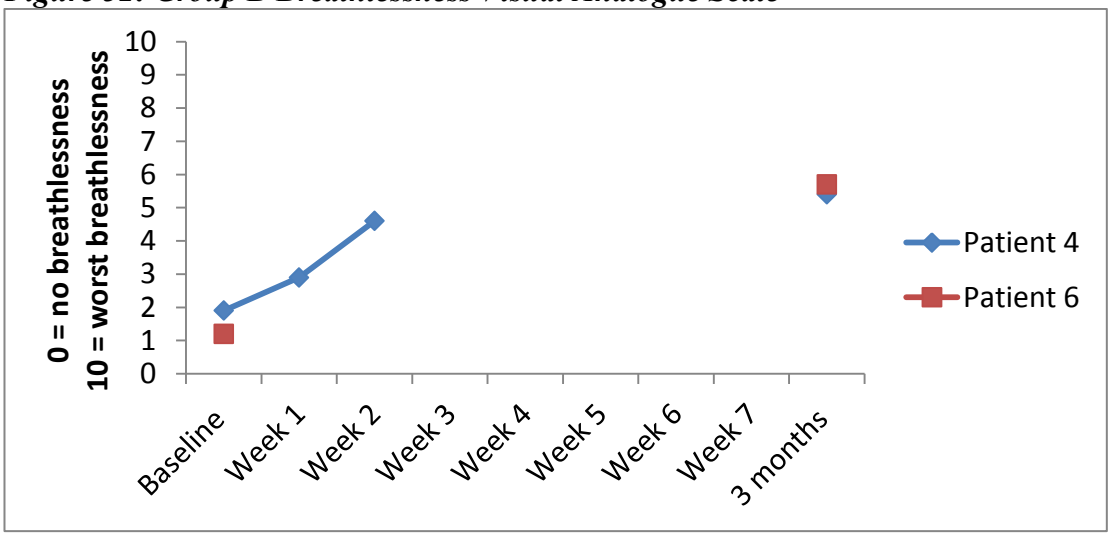


Figure 33: Group B Appetite Visual Analogue Scale

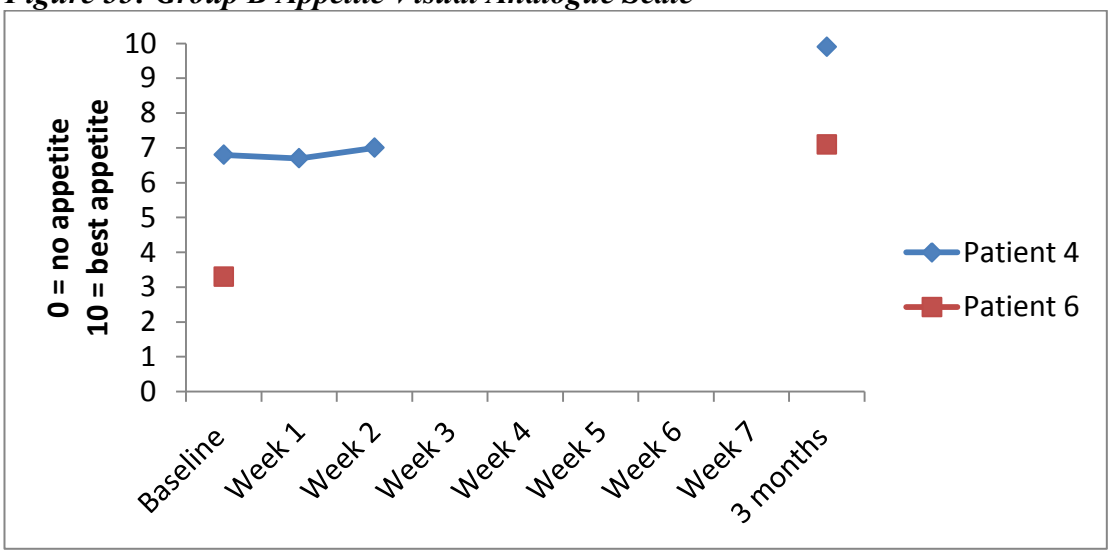


Figure 34: Group B Pain Visual Analogue Scale

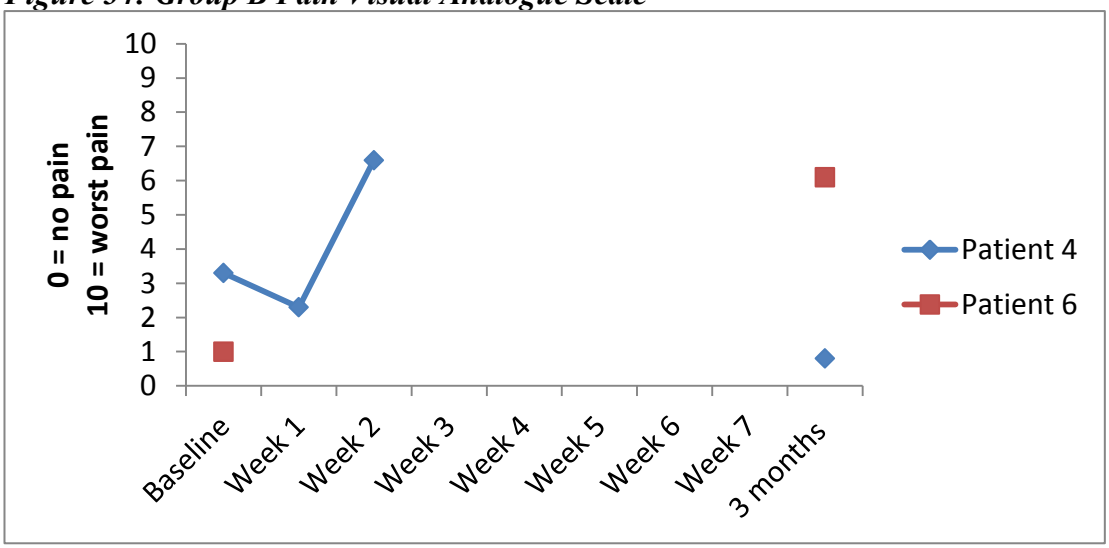
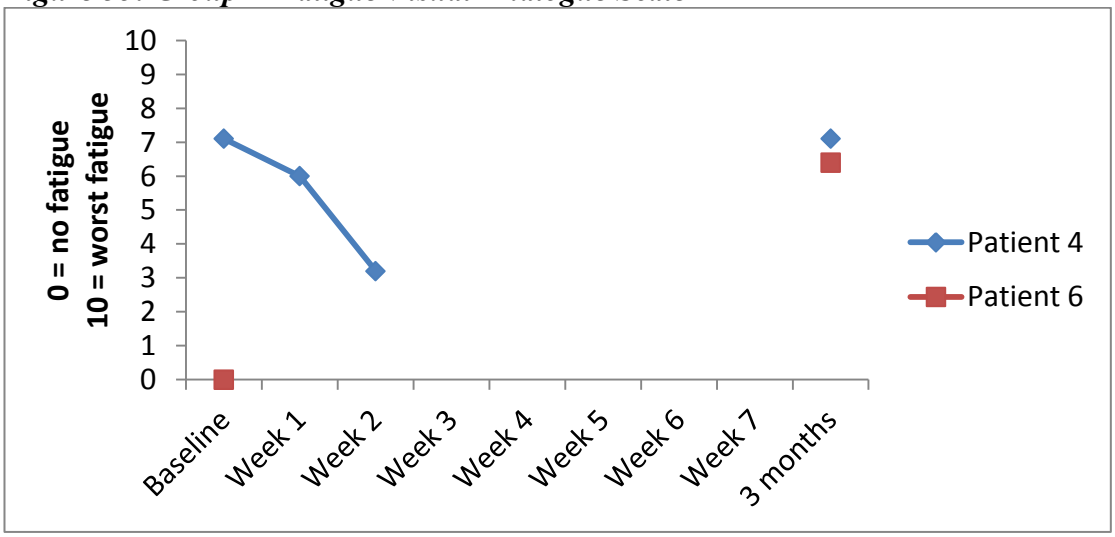


Figure 35: Group B Fatigue Visual Analogue Scale



Although as previously mentioned Group B has small numbers, it is interesting to note that patients in this group reported the lowest problems with breathlessness, pain and fatigue and had a similar appetite score to those in group A.

6.4.2 Group D

Group D consisted of one patient who was malnourished on discharge from ICU and at three months post ICU discharge was classified as well-nourished using Subjective Global Assessment.

6.4.2.1 Nutritional Intake

The results for group D suggest that the patient was meeting his estimated calorie and protein requirements during his ward stay (table 21). Although there is only one patient in the group D which limits comparison with the other groups, the results showed that nutritional intake during ward stay was highest across all the groups.

However, nutritional intake for group D at three months post ICU discharge was less than 50% of ward intake (table 22). These data were counter-intuitive as the patient's nutritional status improved over the three month period and therefore it would be expected that his three month intake would be higher.

Table 21: Calorie and Protein Intake as a % of Nutritional Requirements During Ward Stay

	Group D n=1
Ward Stay	Patient 9
Mean calorie intake (% of req)	110
Mean protein intake (% of req)	97

Table 22: Calorie and Protein Intake as a % of Nutritional Requirements at 3 Months Post ICU discharge

	Group D n=1
3 months post ICU discharge	Patient 9
Mean calorie intake (% of req)	48
Mean protein intake (% of req)	39

Individual calorie and protein intakes as a percentage of nutritional requirements in group D are presented in figures 36 and 37.

Figure 36: Group D Calorie Intake as a Percentage of Requirements

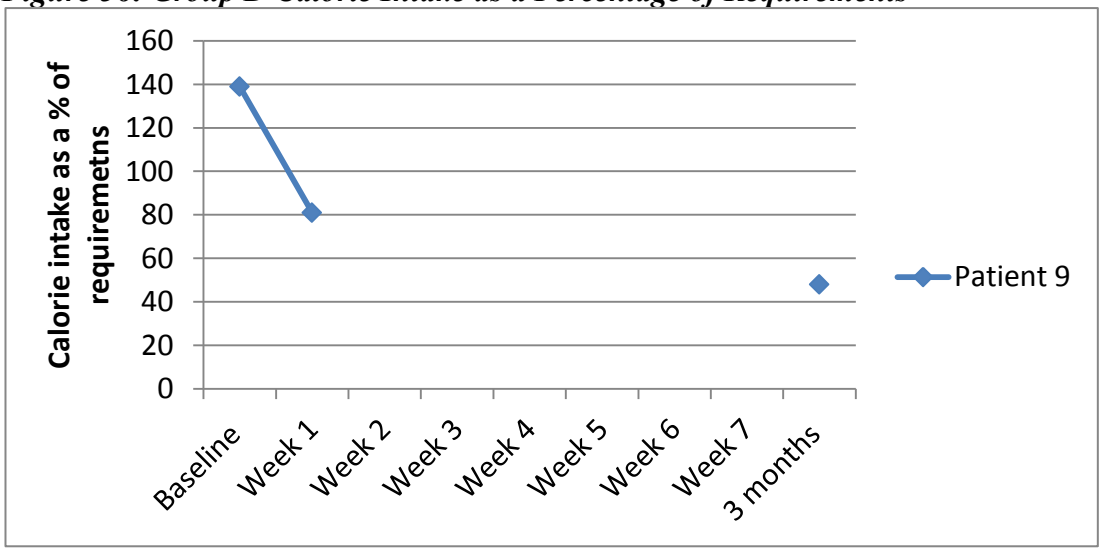
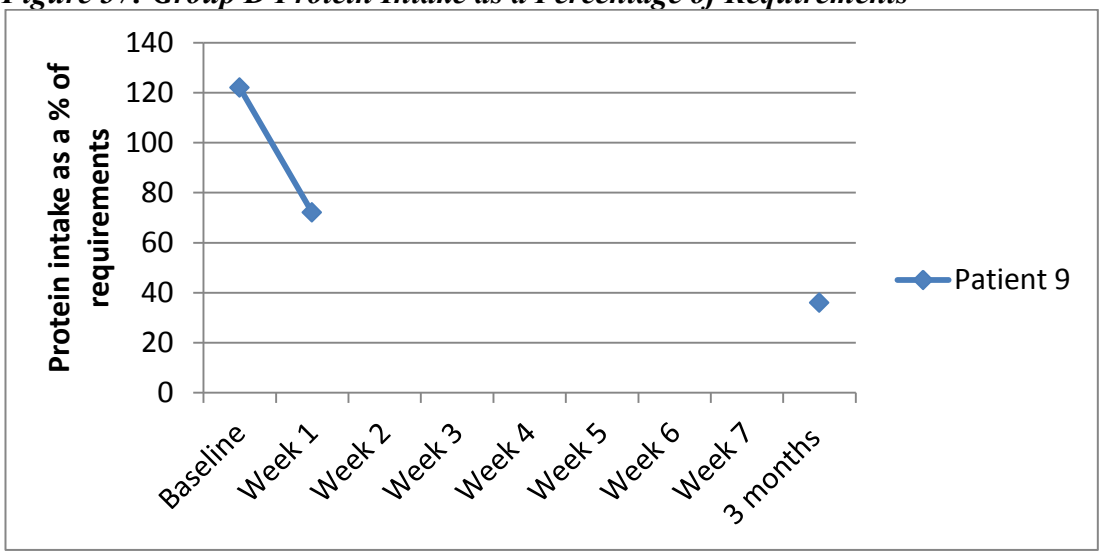


Figure 37: Group D Protein Intake as a Percentage of Requirements



6.4.2.2 Visual Analogue Scales

As described previously, the mean value of the patient's VAS was calculated for the duration of their ward stay. Table 23 summarises the ward scores of VAS in group D.

Table 23: Mean VAS Scores During Ward Stay

	Group D n=1
Ward Stay	Patient 9
Mean VAS Breathlessness	0.85
Mean VAS Appetite	7.3
Mean VAS Pain	1.05
Mean VAS Fatigue	7.3

Although there was only one patient in group D, his mean scores for breathlessness and pain were the lowest out of all the groups and his mean appetite score was higher than the other groups. Interestingly, the results indicated a high level of fatigue during his ward stay.

The results of the VAS scores at 3 months post ICU discharge for group D are presented in table 24.

Table 24: VAS Scores at 3 Months Post ICU Discharge

	Group D n=1
3 months post ICU discharge	Patient 9
VAS Breathlessness	0.9
VAS Appetite	7.9
VAS Pain	3.1
VAS Fatigue	3.9

The results suggest that the patient experienced more pain and fatigue at three months than during his hospital stay.

Individual VAS for breathlessness, appetite, pain and fatigue for group D from transfer from ICU to three months post ICU discharge are presented in figures 38 to 41.

Figure 38: Group D Breathlessness Visual Analogue Scale

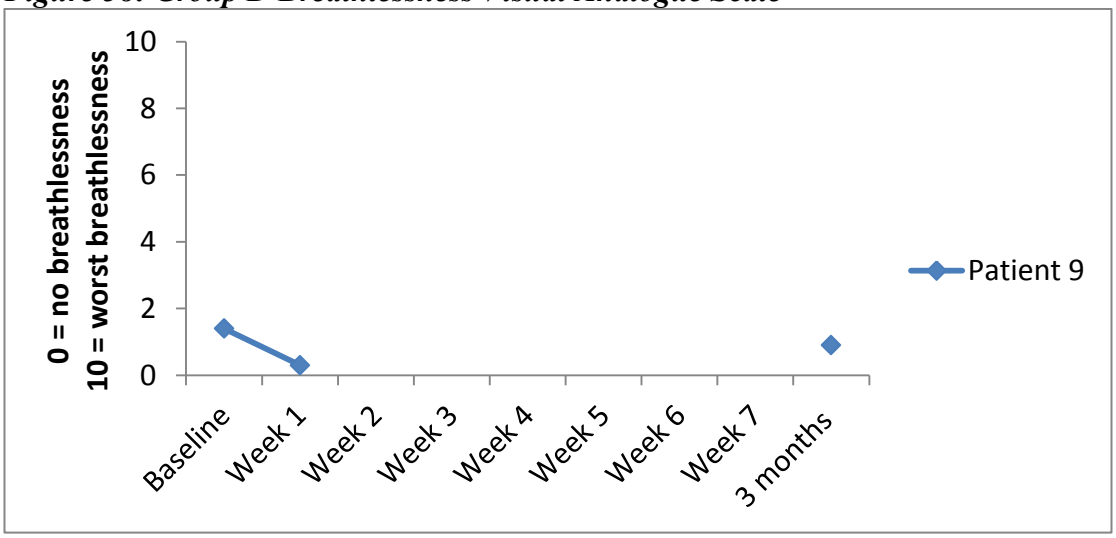


Figure 39: Group D Appetite Visual Analogue Scale

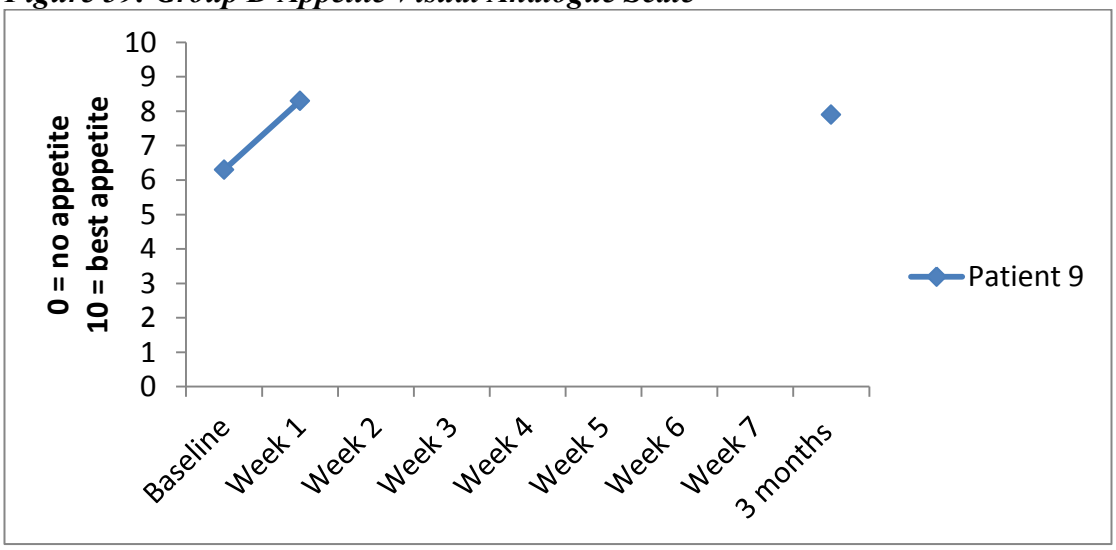


Figure 40: Group D Pain Visual Analogue Scale

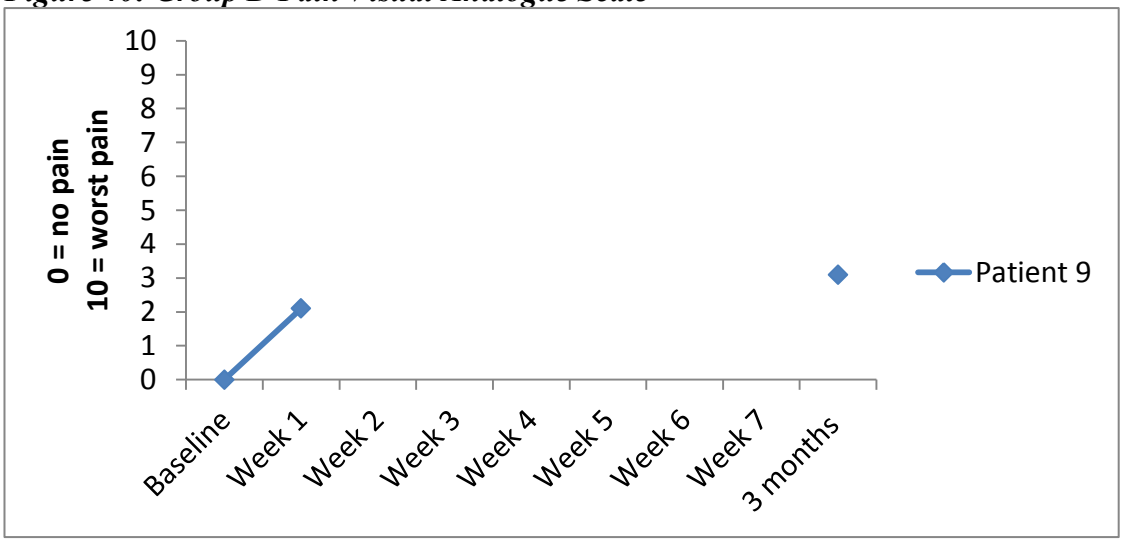
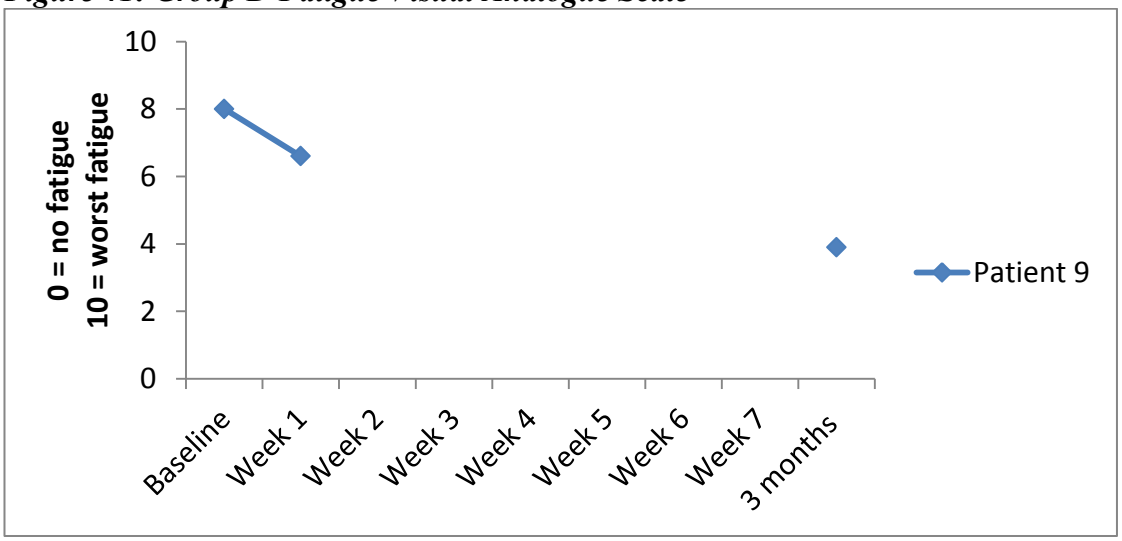


Figure 41: Group D Fatigue Visual Analogue Scale



6.5 Impact of changing ward care on nutritional outcome

The 14 patients with complete data sets were then categorised into their RECOVER study groups. Seven patients in the control group received standard ward care and the other seven had enhanced nutritional and physiotherapy care as part of the intervention group of the RECOVER study (Appendix7).

6.5.1 Patient Characteristics

The characteristics of the patients in the intervention and control group analysis are displayed in table 25.

Table 25: Patient Characteristics

	Intervention n=7		**Control** n=7	
	Median (IQR)	Min Max	Median (IQR)	Min Max
Age (years)	50 (39-69)	31 70	60 (52-70)	42 93
Apache II*	20 (17-27)	7 28	18 (12-27)	11 30
Length of ventilation (days)	13 (6-27)	4 41	23 (3-32)	3 41
Length of ward stay (days)	14 (6-28)	6 53	8 (4-14)	4 33
Total acute hospital stay (days)	28 (15-73)	12 95	34 (11-40)	10 79

*Apache II (Acute Physiology and Chronic Health Evaluation II) is a severity-of-disease classification system used in ICU (Knaus et al 1985). A score from 0 to 71 is calculated based on several measurements; higher scores correspond to more severe disease and a higher risk of death.

It is of interest to note that the patients in the control group tended to be older and had more ventilation days than those in the intervention group

6.5.2 Nutritional Intake

The nutritional intake of each patient was assessed on transfer from ICU to the ward and weekly thereafter during their stay on the ward. The mean for each patient's calorie and protein intake as a percentage of their nutritional requirements was calculated for the duration of their ward stay. Table 26 summarises the protein and calorie intake as a percentage of nutritional requirements in the two groups.

Table 26: Calorie and Protein Intake as a % of Nutritional Requirements During Ward Stay

	Intervention n=7		**Control** n=7	
Ward Stay	Median (IQR)	Min Max	Median (IQR)	Min Max
Mean calorie intake (% of req)	87.5 (70-94)	48 124	55 (33-96)	29.5 110
Mean protein intake (% of req)	70.76 (40-82.75)	33 109.71	70.5 (32.5-83)	18 97

The results suggest that across both groups patients were not meeting their nutritional requirements i.e. not achieving 100% of their calorie and protein requirements which would be necessary to maintain their weight. Figure 42 highlights the trend towards higher calorie intakes in the intervention group compared to those in the control group. Protein intakes during hospital stay were similar across the two groups (figure 43).

Figure 42: Calorie Intake as a % of Nutritional Requirements During Ward Stay

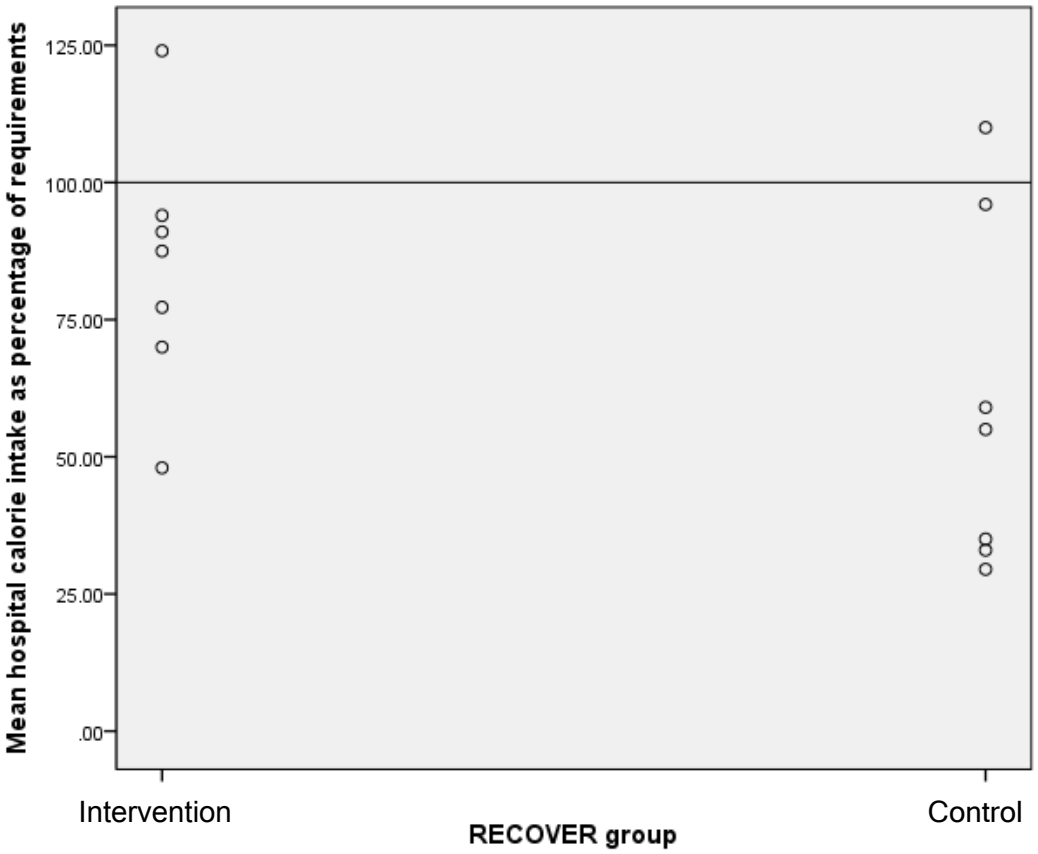
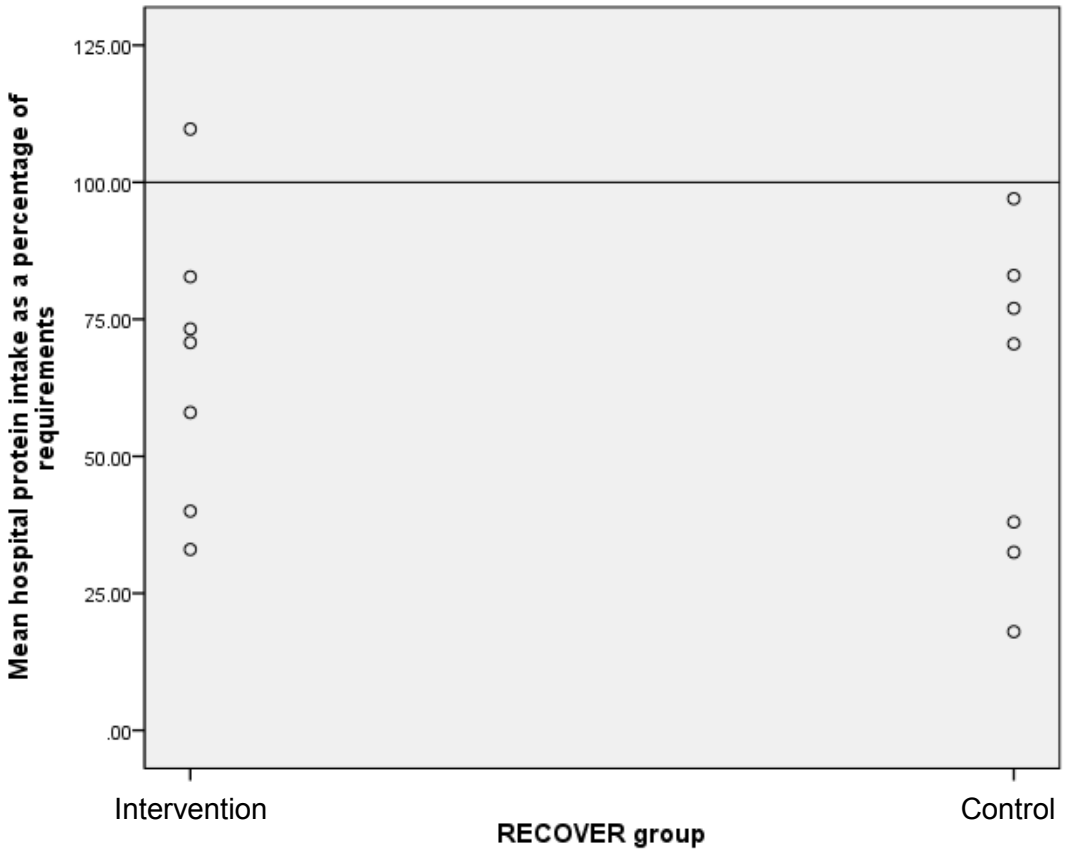


Figure 43: Protein Intake as a % of Nutritional Requirements During Ward Stay



Calorie and protein intakes as a percentage of nutritional requirements were then compared across the two groups at three months post ICU discharge. The results are presented in table 27.

Table 27: Calorie and Protein Intake as a % of Nutritional Requirements at 3 Months Post ICU discharge

	Intervention n=6		**Control** n=7	
3 months post ICU discharge	Median (IQR)	Min Max	Median (IQR)	Min Max
Mean calorie intake (% of req)	87 (82.25-101)	71 116	88 (52-94)	48 101
Mean protein intake (% of req)	82 (74-107.25)	68 108	69 (49-84)	39 97

At three months both groups were achieving similar calorie intakes in relation to their nutritional requirements. The control group had lower protein intakes

compared to the intervention group. Mean calorie and protein intakes as a percentage of requirements in the two groups are shown in figures 44 and 45.

Figure 44: Calorie Intake as a % of Nutritional Requirements at 3 Months Post ICU discharge

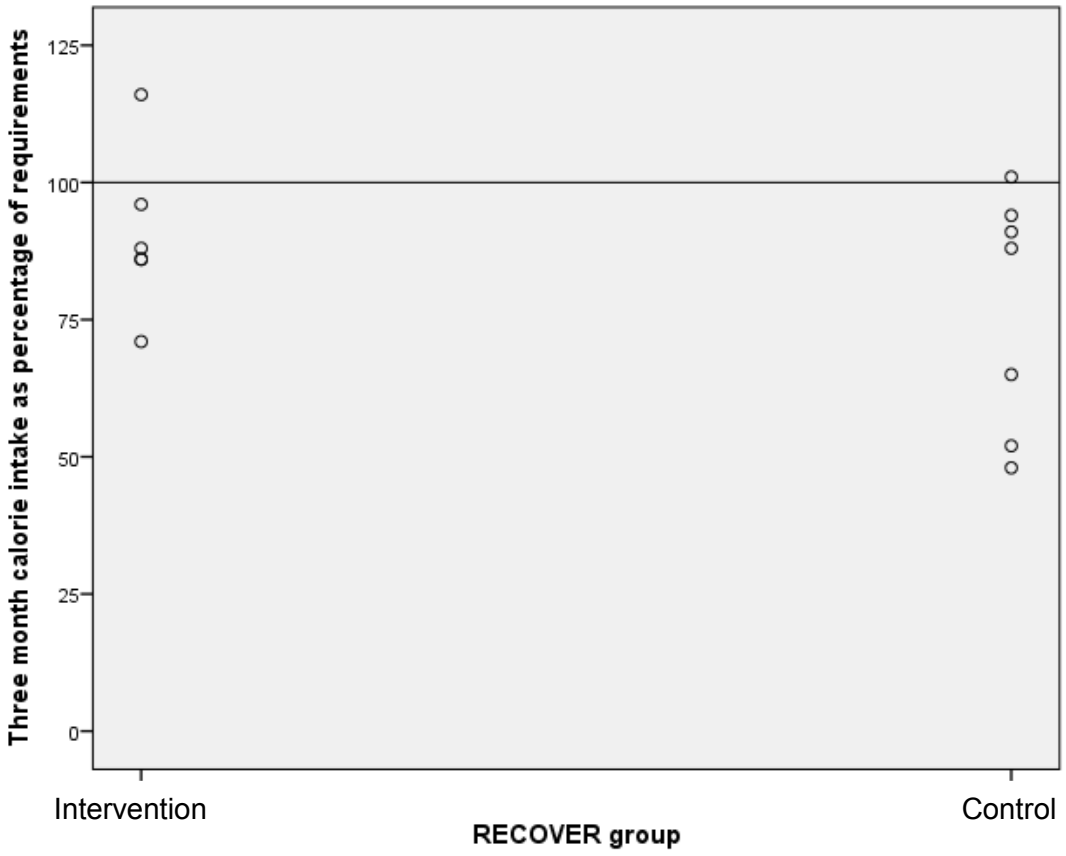
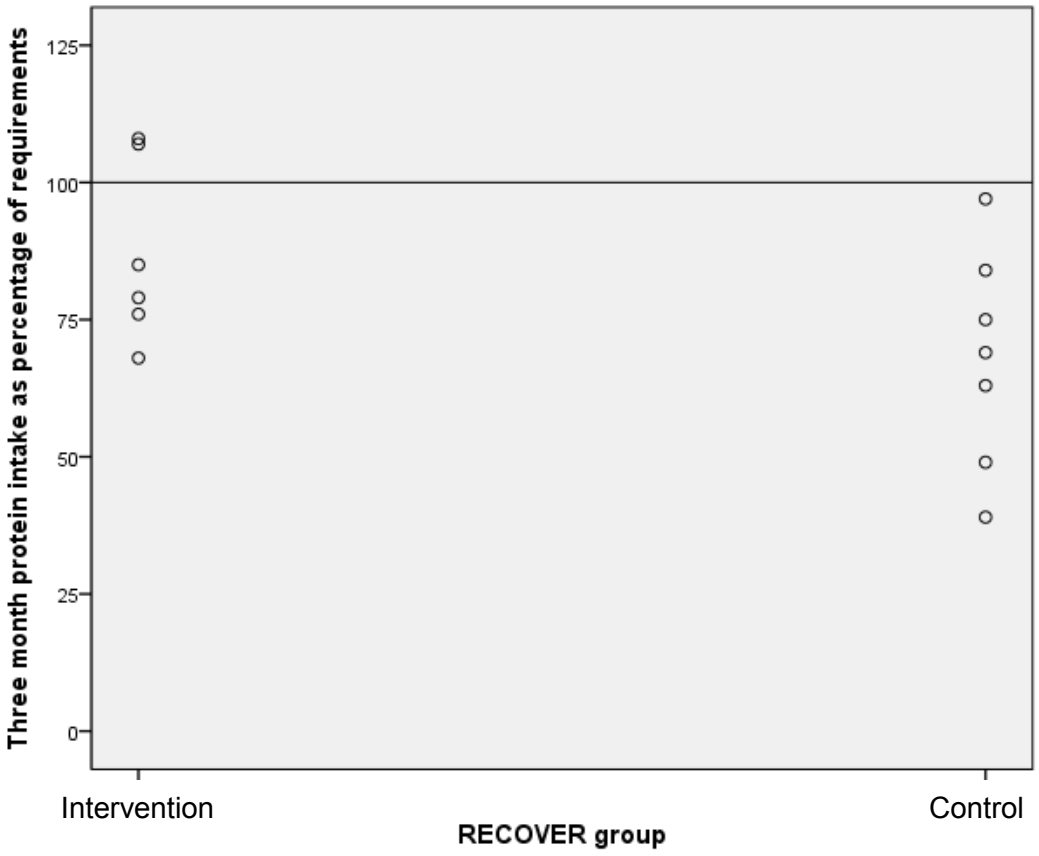


Figure 45: Protein Intake as a % of Nutritional Requirements at 3 Months Post ICU discharge



6.5.3 Visual Analogue Scales

Visual analogue scales (VAS) for breathlessness, appetite, pain and fatigue were measured on transfer to the ward and weekly thereafter during their ward stay. The scales range from 0 to 10 with 0 being no breathlessness, appetite, pain or fatigue to 10 which is the worst breathlessness, best appetite, worst pain and worst fatigue. As described previously, the mean for each patient's VAS was calculated for the duration of their ward stay. Table 28 summarises the VAS measurements across the two groups.

Table 28: VAS Scores During Ward Stay

	Intervention n=7		Control n=7	
Ward Stay	Median (IQR)	Min Max	Median (IQR)	Min Max
Mean VAS Breathlessness	2.9 (1.2-4.1)	1.07 6.1	2.3 (0.85-5.2)	0.8 8.3
Mean VAS Appetite	3.37 (2.4-6.2)	2.1 7.4	6.83 (2.4-8.2)	0.6 8.5
Mean VAS Pain	1.6 (0.9-6.26)	0.17 6.7	3.1 (1.05-8.1)	0 9.5
Mean VAS Fatigue	6.95 (3.3-8.5)	0 8.8	5.6 (5.2-7.6)	4.7 9.3

The VAS scores were then compared between the two groups at three months post ICU discharge. The results are presented in table 29.

Table 29: VAS Scores at 3 Months Post ICU Discharge

	Intervention n=7		Control n=7	
3 months post ICU discharge	Median (IQR)	Min Max	Median (IQR)	Min Max
VAS Breathlessness	2.4 (0.8-5.7)	0.7 7.1	5.4 (1.4-5.9)	0.9 7.4
VAS Appetite	7.4 (4.8-8.9)	2 9	4.1 (2.3-7.9)	1.5 9.9
VAS Pain	1.6 (0.9-6.1)	0 6.2	3.1 (0.8-5.1)	0 5.2
VAS Fatigue	4.7 (4.2-6.2)	1.3 7.8	6.1 (3.9-7.8)	0.8 8.8

6.6 Complementarity Interpretation of Quantitative Data with Qualitative Findings

As detailed in chapter 4 the researcher used quantitative and qualitative methods in a complementarity mixed method study to enable "*elaboration, enhancement, illustration, clarification of the results from one method with the results from the other method*" (Greene et al 1989 p259). This section will discuss the results from all of the quantitative data in light of the findings from the qualitative data in order to elicit similar and contrasting results relating to nutritional recovery.

6.6.1 Universal failure to achieve nutritional requirements during ward stay

The majority of patients across the four groups (A,B,C and D) consistently failed to meet their nutritional targets. This was demonstrated by the results from the quantitative analysis of nutritional intake and also the findings from the qualitative data (Chapter 5).

In a normal healthy individual it is generally accepted that an energy deficit of 500kcals a day over a 7 day period is equivalent to 1 pound (0.45kg) weight loss although this is influenced by overall percentage of body fat (Hall 2007). Therefore for a healthy man with an estimated calorie requirement of 2000kcals, consuming a daily calorie intake which met 75% of his requirements would be expected to lead to a weight loss of approximately 1 pound (0.45kg) per week.

Critical illness increases energy expenditure resulting in increased weight loss (Hoffer & Bistrian 2013). Muscle wasting is accelerated due to activation of a systemic inflammatory response. Elevated levels of inflammatory cytokines result in inhibition of protein synthesis, inhibition of muscle cell differentiation and reduced amino acid uptake (Zamir et al 1993). The prevalence of persistent inflammation in post ICU patients is poorly understood although the findings from one small study which measured inflammation beyond the ICU suggested that there was an association between on-going inflammation and poorer physical function (Bateman et al 2009).

Overall, the quantitative results from the doctoral study indicated that the majority of patients did not meet 100% of their estimated calorie and protein requirements necessary to maintain weight during hospital stay. This was also shown in the qualitative data where many patients' accounts highlighted their struggles with eating. This was particularly evident in the accounts from the initial period on the ward after transfer from ICU.

As previously highlighted, the quantitative analysis looking at the two main subgroups A (patients who remained well-nourished) and C (patients who remained malnourished) showed that both groups did not meet their estimated nutritional requirements. Findings from the qualitative accounts highlighted other factors that influenced nutritional intake. The quantitative and qualitative findings from the patients in groups A and C are described below.

The recorded individual calorie and protein intakes for the two patients in group A who had a documented alcohol dependency were consistent with accounts of their nutritional intake. Although from the quantitative data neither were meeting their nutritional intake on transfer from ICU, the data showed that for one of the patients, patient 2 who had a 14 day ward stay, his intake increased beyond his estimated calorie and protein requirements for weight maintenance. The other patient only had a four day ward stay so only the initial data on transfer to the ward was available.

For the remaining four patients in group A, only three have baseline quantitative data as they were discharged home within a week. Their calorie and protein intake did not meet their nutritional requirements and this is consistent with their accounts from the qualitative data describing their problems with food intake. The final patient in group A, patient 17 was receiving enteral nutrition to supplement his oral intake on transfer to the ward, hence was fully meeting his estimated calorie and protein requirements. Week 2 showed a reduction in his nutritional intake and this was associated with removal of his nasogastric tube. By week three however his oral nutrition was sufficient to meet 100% of his requirements. Again this was consistent with his account of his intake which was minimal initially on transfer to the ward but was supported with enteral nutrition.

Four out of the five patients in group C were meeting less than 60% and less than 80% of their estimated calorie and protein requirements respectively on discharge from ICU. This was again consistent with their accounts from the qualitative data that described the difficulties they were having with eating. The one patient who was meeting her nutritional requirements on transfer to the ward was receiving enteral

nutrition to supplement her oral intake. Another patient was started on a nasogastric feed during his ward stay due to a combination of poor oral intake and pre-existing malnutrition.

The quantitative results suggested that overall during their ward stay group C tended to meet a higher percentage of their calorie and protein intake compared with group A. However, as previously mentioned, two patients from group C received enteral nutrition in addition to oral diet and this would have significantly increased their overall calorie and protein intake.

The quantitative assessment of nutritional intake clearly showed that the only patients who consistently met their nutritional requirements during their hospital stay were those who received artificial nutritional support. This method of feeding circumvented the factors that were associated with a reduced oral intake. These included patient related factors including physiological and psychosocial issues and organisational issues (chapter 5).

It could be argued however that assessment of nutritional intake is not always accurate. Nutritional intakes were obtained from observations of meals and from questioning patients and staff. Weighed food intakes would have been more accurate than estimated served weights in calculating energy and protein consumption however this is a laborious process (Livingstone et al 1990). Reliability of the information is another potential problem as some foods may have been omitted and average weekly nutritional intakes was calculated from a three day food chart. Similarly, nutritional requirements were estimated using a predictive formula that took into account the patient's age, sex, weight, activity and stress factor. Studies have shown that predictive equations do not accurately predict energy expenditure (Reid 2007). Despite these methodological limitations, the findings from the doctoral study suggest that post ICU patients experience poor nutritional intakes during their ward stay.

6.6.2 Nutritional intake in hospital was a poor predictor of nutritional outcome

At three months post ICU discharge the patients in both groups A and C showed an increase in calorie and protein intake compared to their ward stay data. It was noted that although intakes had improved overall, both groups still failed to achieve their nutritional targets at three months. Any concurrent changes in nutritional status over the first three months after ICU discharge was difficult to measure as weight, which is the most frequently used clinical measurement was affected by the presence of ascites and oedema. The SGA tool which was used in the study provided an indication of nutritional status on discharge from ICU and at three months post ICU discharge. However, the SGA is not designed to measure changes in body composition and was used simply to assess overall nutritional status at the two time points. It is hypothesised that in order to fully assess the impact of a nutritional intervention on body composition imaging technologies would need to be employed to assess fat distribution and muscle depth.

Individual patient data demonstrated that by three months post ICU discharge nutritional intakes had often increased or decreased for a variety of reasons. Two patients in group A reported a reduction in food intake at three months in their qualitative accounts. Both patients described a return to previous lifestyle habits including alcohol excess, smoking and drug use. This was evident in the quantitative data which showed decreased protein and calorie intakes from their ward stay. Patient 2 had a significantly decreased calorie intake at three months in comparison to his ward data despite inclusion of the calories from alcohol. Surprisingly his protein intake as a percentage of his requirements at three months, although lower than during ward stay, was higher than his calorie intake. Patient 7, as previously described had a very short ward stay therefore only the baseline data was available. However his intake had increased since hospital although a significant proportion of his calorie intake was from alcohol consumption.

Patient 17 reported in his qualitative account that his intake had deteriorated since hospital discharge. The quantitative data demonstrated a slight decrease in calorie

intake however his protein intake as a percentage of nutritional requirements was higher than the ward data. He was still taking his nutritional supplements which would account for some of his nutritional intake. Patient 16 described his nutritional intake at three months as similar to his intake prior to discharge from the ward. He had a short ward stay and hence only has baseline quantitative data; therefore accurate comparisons could not be made.

The two other patients in group A reported that their nutritional intake had improved since hospital discharge. The quantitative data for patients 12 and 13 was consistent with their accounts and demonstrated an increase in calorie and protein intake since hospital discharge. However neither patients were meeting 100% of their estimated nutritional requirements at three months and both had reported associated further weight loss since hospital discharge.

Conversely, all five patients in group C reported an increase in their food intake at three months in their qualitative accounts. The quantitative data indicated that three out of the five patients had increased calorie and protein intakes compared with ward data. For the two patients whose food diaries showed that their nutritional intake was lower than ward data, one was a very elderly lady, patient 11, who lived alone and struggled with cooking. The other one was patient 3 who had contracted a viral illness since discharge from hospital which resulted in him feeling very unwell and thus had adversely affected nutritional intake.

The results from group B and D were counter intuitive although the small numbers in the groups limit the generalisability of the findings. The quantitative results suggested that nutritional intake was higher at three months post ICU discharge in group B but the patients' nutritional status had deteriorated from well-nourished to malnourished during that time period. Conversely, the quantitative results for group D suggest that nutritional intake had decreased at three months post ICU discharge despite the fact that the patient's nutritional status improved from malnourished to well-nourished.

These findings suggested that current dietetic practice, which involves recording and calculating nutritional intake and requirements, provides a poor indicator of eventual nutritional outcome. It was apparent that many other factors influenced the nutritional outcome and brings into question the value of measuring nutritional intake, which is a time consuming, labour intensive task. Additionally the data also suggested that the malnourished patients achieved similar, if not slightly better nutritional intakes than the well-nourished group. This challenges the role of the dietitian and the nature of the interventions needed for this patient group.

The quantitative data also revealed that patients in the intervention group of RECOVER showed a trend towards a higher calorie intake compared to the control group during their hospital stay. These results suggested that input from the Generic Rehabilitation Assistants (GRAs) may be improving calorie intake during hospital stay. The GRAs facilitated nutritional care by improving communication between ward staff and dietetic staff, circumvention of the delivery system for snacks and supplements and provision of regular monitoring and feedback of nutritional intake. These interventions could have contributed to the trend to improved calorie intake.

6.6.3 Influence of nutritional intake on body composition

It is well documented that patients lose muscle mass during ICU stay, however little work has been done to establish body mass recovery after critical illness. It is postulated that the universal low protein intake which was demonstrated in the study may lead to an increase in fat stores, not the more desirable recovery of muscle mass. Research has shown that acutely ill patients showed a preference for high calorie, low protein foods (Winograd & Brown 1990). Animal studies have highlighted that this disposition for high calorie, low protein foods may be related to increased levels of inflammatory cytokines (MacDonald et al 1995). As previously mentioned it is likely that post ICU patients have on-going inflammation which may in part account for the low protein intakes.

Another issue relating to protein intake is the limited evidence to determine protein requirements for this patient population. A recent systematic review demonstrated

the limited and poor quality evidence regarding protein provision in critical illness. However the studies showed that increasing protein intake was associated with an improved nitrogen balance (Hoffer & Bistrian 2012). The review suggested that protein requirements are elevated in critical illness in order to improve body protein economy; however most patients receive less than half of the current recommended protein intakes (Hoffer & Bistrian 2012). It is not known whether increasing protein intake is associated with improvements in lean body mass. It has been suggested that since many post ICU patients have an on-going inflammatory response, it is possible that protein requirements would be similar to those in ICU.

6.6.4 Nutritional status remained unchanged over three month time period

Quantitative data highlighted minimal changes in nutritional classification during the first three months post ICU discharge. Six out of 8 patients remained well-nourished and 5 out of 6 patients remained malnourished at three months post ICU discharge. However, as previously highlighted the SGA tool was used to provide a broad classification of nutritional status and does not detect changes in body composition. A patient's nutritional status may have altered within a category i.e. a patient could have become more malnourished. More accurate measurements of body composition would be necessary to discern changes in nutritional status. The researcher argues that the results from the quantitative data suggest that patients remain on relatively fixed trajectories from ICU discharge. Current nutritional care interventions do not appear to be effective in influencing these trajectories which is a concern for patients who are malnourished on discharge from ICU.

The findings from the qualitative data suggest that the majority of patients experienced weight loss after their ICU stay although the extent of weight loss was often masked by the presence of peripheral oedema. Three patients who were overweight before admission to ICU were pleased that their weight had reduced. Those who were malnourished on ICU discharge expressed concern about their weight loss with similar concerns voiced at the three month interviews.

6.6.5 Universal experience of physiological issues

Both groups reported problems with physiological barriers to intake, especially poor appetite and fatigue. This was consistent across the visual analogue scale (VAS) scores in the two groups. The VAS scores were compared across the two groups using a 75% cut-off value. This value was applied pragmatically to highlight the higher scores across the groups.

All the patients in groups A and C indicated the presence of fatigue in their initial interview and this is reflected in the VAS scores. Four out of the six patients in group A reported a fatigue score above 75% of the scale with a similar proportion, 3 out of the 5 patients, in group C reporting an initial fatigue score above 75%.

Four out of six patients in group A reported that they had a poor appetite on transfer to the ward in their qualitative accounts although only two (patient 13 and patient 17) out of the four had given a score less than five. Patient 17 had a prolonged ward stay and his appetite scores improved weekly and this was consistent with the descriptions from his qualitative accounts. Overall, 3 out of the 6 patients in group A indicated an appetite of 75% or less on the scale.

The problem with poor appetite was also suggested in group C as three patients in group C reported that they had a poor appetite on transfer to the ward in their qualitative accounts although four patients gave a VAS score of two or less. For the two patients who had prolonged ward stays, their scores were consistent with their qualitative accounts. Patient 14 reported a very poor appetite initially and it improved over the weeks whereas patient 15 had a poor appetite on transfer to the ward and it continued to deteriorate during the three weeks of his ward stay. Four out of the five patients in group C indicated a self-reported appetite score below 75% of the scale.

6.6.6 Inconsistencies between reported VAS scores and qualitative accounts

It was noted that there were some discrepancies between VAS scores and patient accounts. This was particularly evident with breathlessness where only one patient out of the eleven across the two groups specifically mentioned breathlessness in their qualitative accounts, yet all patients clearly felt that they were experiencing some breathlessness as evident from their VAS scores. One patient reported an initial breathlessness score of above 75% of the scale with 3 out of the 11 patients reporting a breathlessness score of above 50%.

Group A reported worse breathlessness than group C yet no one mentioned breathlessness in their qualitative accounts. For those patients who had ward stays of longer than a week, the reported scores for breathlessness decreased over the period of their stay.

Only one patient in group C, patient 15, mentioned breathlessness in his qualitative account. His score on transfer to the ward was the highest in the group and subsequent scores during his three week ward stay indicated that his breathlessness was getting worse. He talked about his breathlessness in every interview and it was evident that this was really bothering him.

Further inconsistencies were noted in patients' experiences of pain in their qualitative accounts and subsequent VAS scores. Two patients out of the eleven across the two groups specifically mentioned pain in their qualitative accounts yet all patients clearly felt that they were experiencing some pain as indicated from their visual analogue scale scores (VAS). Three out of the eleven patients reported initial pain scores of 75% or above on the scale.

In group A patient 13, who specifically mentioned pain in her qualitative account, gave a score of less than one in her VAS. Patients 7, 16 and 17 gave very high VAS scores for pain yet did not mention the presence of pain in their interviews. In group C four patients gave a low score for pain and did not mention it in their ward

accounts. The other patient (patient 14) in the group gave a high initial VAS pain score and the scores indicated the presence of pain throughout her ward stay. This was consistent with her qualitative accounts as she mentioned the presence of pain in each of her weekly interviews.

Interestingly, although pain was not frequently mentioned in the qualitative interviews, pain was found to be correlated with reduced oral intake. Surgical patients, particularly those with pancreatitis, experienced the most problems with pain and this may well have been a contributory factor to the poor oral intakes recorded in this patient group.

6.6.7 Variable improvement in physiological issues over time

It was evident that some of the results from VAS over the three month period were counter intuitive. For example it was noted that the median breathlessness scores in group A at three months were higher compared with ward scores. Additionally appetite scores improved in group C at three months compared with ward scores but the results from group A indicated that appetite was decreased at three months when compared with ward scores.

Similarly the results from group B were also counter intuitive as the VAS scores for breathlessness, pain and fatigue were lower than the scores in groups A and C during ward stay. Additionally, appetite scores for group B had improved at three months despite the fact that the patients' nutritional status had deteriorated from well-nourished to malnourished during the three month period.

These findings suggest that the presence of these physiological issues such as poor appetite, fatigue, breathlessness or pain are unreliable discriminators in determining eventual nutritional outcome, at least when assessed using VAS. The data suggest they have no predictive value as a screening tool. A possible confounding issue is that breathlessness, and to a lesser extent fatigue and pain, were likely to have been affected by increasing activity levels. Patients in the intervention group of RECOVER were likely to have experienced increased levels of breathlessness as part

of the role of the GRA was to provide enhanced physical rehabilitation. Therefore the variation in the VAS scores could be related to differing activity levels.

6.6.8 Impact of limited dietetic resources

It was noted that despite the fact that all the patients were under the care of the critical care dietitian during their ICU stay, many were not reviewed by a dietitian during their ward stay. Four patients from group A and one from group C were not seen by dietetic staff before discharge from hospital. Hence for the majority of patients in group A any on-going nutritional problems on the ward would not necessarily have been highlighted. Analysis of the whole group showed that the median number of dietetic visits during the first week on the ward was less than one (table 30).

This lack of dietetic intervention has been driven by the need to prioritise patients due to reductions in staffing levels. Higher priority patients, for example referrals for artificial nutritional support, would be seen first and those only on diet or oral nutritional supplements may not always have been reviewed regularly. A typical dietetic intervention would involve calculating nutritional requirements based on the patient's age and weight and an assessment of nutritional intake. Based on the discrepancy of nutritional intake in comparison to requirements, the dietitian would recommend starting the patient on additional snacks and/or oral nutritional supplements. Patients who were unable to meet their nutritional requirements through oral supplementation, particularly those who had lost significant amounts of weight, may have required artificial nutritional support. Again the dietitian would be involved in deciding the most appropriate route, type and amount of artificial nutritional support.

Table 30: Provision of dietetic input during ward stay

Week	Number of Patients on the ward	Total number of times seen by dietitian
		Median (IQR)
1	14	0.5 (0-1.25)
2	5	2 (1-3)
3	4	2 (1-3.75)
4	2	1.5
5	1	2
6	1	1
7	1	1

The GRA from the RECOVER study positively influenced dietetic care as part of their role was to contact dietetic staff when a patient in the study was transferred to the ward. Five out of the 7 patients in the intervention group were seen by a ward dietitian. Only 2 of 7 patients in the control group were seen by the dietitian, with another patient eventually being re-referred to the dietitian by medical staff due to ongoing nutritional problems. Table 31 shows the frequency of visits between the two groups with patients in the intervention group being seen by a dietitian a median of 1-3 times during their ward stay.

Table 31: Provision of dietetic input to control and intervention patients from the RECOVER study

Week	Number of control group patients on ward	Total number of times seen by dietitian	Number of intervention group patients on ward	Total number of times seen by dietitian
		Median (IQR)		Median (IQR)
1	7	0 (0-1)	7	1 (1-2)
2	1	2	4	2 (1-3)
3	1	1	3	3
4	1	1	1	2
5			1	2
6			1	1
7			1	1

6.6.9 Questions raised about acceptability of traditional dietetic interventions

As previously mentioned the majority of patients failed to achieve their estimated nutritional requirements. Three patients in group C were commenced on oral nutritional supplements with the aim of increasing calorie and protein intakes. However from the qualitative accounts it was clear that these were often not well tolerated and numerous incidences of patient refusal was noted from the drug charts, which eventually culminated in the discontinuation of the supplement. One example of this was patient 15 who was seen by the dietitian and started on supplements which initially increased his overall calorie and protein intake. However, as described in his qualitative account, he had difficulties tolerating the supplements as he found them unpalatable. He subsequently refused to take them and this correlated with a decline in his calorie and protein intake from week 2 onwards.

Two patients, one from group A and one from C, consistently achieved a much higher percentage of their estimated nutritional requirements. Both these patients

received enteral nutrition to supplement their oral intake during a protracted ward stay. However the acceptability of this form of nutritional support could be questioned as both patients had on-going problems with nausea and vomiting that resolved when the enteral feed was discontinued. In her qualitative account patient 14 describes on-going issues with nausea and vomiting which she directly attributed to the nasogastric feed that she had been on for two weeks. Antiemetic drugs were prescribed for use as required however they were not written up for regular administration and the patient often had to ask for them. The volume of feed was decreased by nursing staff in an effort to reduce her symptoms.

At the end of week 2 on the ward the decision was made by the medical staff, in conjunction with the ward dietitian to remove the nasogastric tube to ascertain if that alleviated her gastrointestinal symptoms and allowed for an increase in her oral intake. Her calorie and protein intake fell dramatically in week 3 to less than 50% of her requirements as her nutritional intake was solely from food; however her vomiting stopped and her mood improved. Her intake did improve gradually throughout the remainder of her ward stay as demonstrated by increased calorie and protein intakes and by week 7, when she was discharged home, she was meeting 100% of her nutritional requirements necessary to maintain weight.

These issues highlight the need for individualised care where nutritional management is tailored to address the wide range of issues faced by this patient group.

6.6.10 Impact of service based delivery of care on efficacy of nutritional intervention

Pressure on acute care beds has meant that patients are discharged from hospital as early as possible. In this study the median length of ward stay was 8 days and this was the same for both group A and C. However, the interquartile range was smaller in group A and three out of the six patients were discharged home in under a week. For these three patients the only record of their nutritional intake was from initial food charts which showed that they were meeting less than half of their estimated calorie and protein requirements. In group C two patients were discharged home in

under a week so only the baseline calorie and protein intake data was available. This short time frame would have limited the effectiveness of any nutritional intervention.

The quantitative data demonstrated that patients' nutritional status did not markedly change during the three months post ICU discharge. The qualitative findings showed that no patients had any dietetic follow up since discharge from hospital although it was apparent that many had nutritional concerns. The researcher, as a practising dietitian, provided nutritional advice during many three month follow up interviews.

This again challenges the efficacy of current dietetic practice and suggests the need for a paradigm shift from service based dietetic management to patient based management which would provide continuity of care from hospital to the community setting. This approach corresponds with the current government drive to improve 'care' not 'treatment'.

6.6.11 What drives nutritional recovery?

The findings from the data suggest that resolution of the underlying illness and its associated symptoms was more influential for nutritional recovery than current dietetic interventions. It was clearly demonstrated that despite dietetic preoccupation with setting nutritional targets, these were not achieved by the majority of patients. The differences in nutritional intake during ward stay which was demonstrated in the RECOVER study was not maintained at three months post ICU discharge as the control group achieved a similar calorie intake. Aggressive use of nutritional support to achieve nutritional requirements was not well tolerated by patients with uncertainty surrounding the benefits of improved nutritional intake which cannot be answered from this doctoral study.

It is postulated that a more effective nutritional intervention would be the provision of patient centred care. This would involve working with the patient to set goals according to their individual needs and preferences in order to optimise nutritional intake. The approach may also necessitate recognising and attempting to alleviate some of the symptoms associated with the underlying illness.

6.7 Summary of Chapter

As the research was based on a complementarity mixed method study, the results from the quantitative data were explored in relation to the qualitative data to provide a detailed understanding of nutritional recovery in the post ICU patient. The results demonstrated that, in general, patients' nutritional status did not change over the three month period and they remained either well-nourished or malnourished. All patients failed to achieve their calorie and protein requirements during their ward stay and although intakes had improved by three months post intensive care discharge, these still fell short of calculated targets. The subjective measures demonstrated that all patients experienced physiological issues including poor appetite, breathlessness, fatigue and pain on discharge from intensive care, with variable improvement of these over time. There was a poor relationship between quantitively assessed nutritional intake and eventual nutritional outcome. Overall it was highlighted that existing service organisation did not achieve traditional nutritional goals and questions were raised about the acceptability and efficacy of current dietetic interventions for this patient group.

The next chapter presents the substantive theory developed from the grounded theory analysis. *'Interrelated system breakdowns during the nutritional recovery process*' emerged as the overarching core category that influenced patients' experiences of eating after critical illness. This encompassed the categories *'experiencing a dysfunctional body*', '*experiencing socio-cultural changes in relation to eating'* and '*encountering nutritional care delivery failures*'. Each of these categories is described in detail in the next chapter.

Chapter 7 Interrelated System Breakdowns during the Nutritional Recovery Process

7.1 Overview of chapter

The purpose of this chapter is to present the substantive theory that emerged from the data. 'Interrelated system breakdowns during the nutritional recovery process' emerged as the overarching core category which influenced patients' experiences of eating after critical illness. This encompassed the categories 'experiencing a dysfunctional body', 'experiencing socio-cultural changes in relation to eating' and 'encountering organisational nutritional care delivery failures'. These categories are described in three sections in which connections between each category and the core category are highlighted. The first section describes patients' experiences of a dysfunctional body after critical illness and how this influences their relationship with food. The second section examines the social and cultural aspects of eating in relation to post ICU patients. The third section explores the impact of the organisation on patients' experience of nutrition after critical illness. Finally, section 4 highlights the impact of system breakdowns during the recovery process, the core category that underpins the other categories and looks at the role of a Generic Rehabilitation Assistant (GRA) in addressing system breakdowns to promote nutritional recovery.

None of the referenced literature in this chapter specifically relates to post ICU patients except the NICE (2009) guidelines on Rehabilitation after Critical Illness. The reason for this is that there is very little literature on nutritional recovery after critical illness; therefore the referenced studies presented here are drawn from a general patient population.

7.2 Introduction

'Interrelated system breakdowns during the nutritional recovery process' emerged as the overarching core category that influenced patients' experiences of eating after critical illness. This encompassed the categories, 'experiencing a dysfunctional body' 'experiencing socio-cultural changes in relation to eating' and 'encountering

nutritional care delivery failures' (figure 46). All three categories were related to the core category and to each other.

Figure 46: Core category, categories and properties

Core Category	**Interrelated system breakdowns during the nutritional recovery process**		
Category	Experiencing a dysfunctional body	Experiencing socio-cultural changes in relation to eating	Encountering organisational nutritional care delivery failures
Properties	Facing physiological changes	Experiencing social isolation	Experiencing system-centred failures
	Facing psychological changes	Struggling to adapt to an unfamiliar culture	Struggling with an inflexible hospital routine
	Dealing with changes to body, self and identity	Importance of food habits and routine	Communication failures
			Staff knowledge gap

Patients' experienced a number of system breakdowns that influenced their nutritional recovery after critical illness. Encountering nutritional care delivery failures (experiencing system-centred failures, struggling with an inflexible hospital routine, communication failures and staff knowledge gap) highlighted the organisational factors which influenced patients' experience of eating. The interaction between these organisational factors and the patients' dysfunctional body highlights the failings of the organisation in responding to and managing a dysfunctional body (facing physiological changes, facing psychological changes, dealing with changes to body, self and identity) and the socio-cultural changes related to eating (experiencing social isolation, struggling to adapt to an unfamiliar culture, importance of food habits and routine).

The categories, their relationship to each other and the core category are described in the subsequent three sections.

Section 1 Experiencing a dysfunctional body

7.3 Introduction

This section examines the first category that emerged from the data: experiencing a dysfunctional body. The properties relating to this category were facing physiological changes, facing psychological changes and dealing with changes to self and identity (figure 47). Post ICU patients experienced profound and dramatic changes to their body and the findings from the interviews are explored in light of the way these bodily alterations impact on food.

Figure 45 Properties relating to the category 'Experiencing a dysfunctional body'

7.3.1 Facing physiological changes

Patients described changes to the way in which they experienced the physiological aspects of eating after ICU. Appetite, taste and satiety were reported to have been particularly affected; this was especially noted during the first few days of transfer to the ward. All patients, whether well-nourished or malnourished, experienced one or more of these physiological changes. The following subsections explore these changes and examine the ways they impact on food intake.

7.3.1.1 Loss of appetite

Loss of appetite was the most commonly reported physiological change after ICU. This persisted for variable lengths of time and for some patients it was still reported as being a problem at three months post ICU discharge. It was noted that the terms

hunger and appetite were used interchangeably by patients as the quotes below illustrate.

"*I couldn't eat when I came out (of ICU) at all, virtually..... I just didn't feel hungry."* (Patient 12)

"*I don't have any appetite. I'm sort of force feeding myself.*" (Patient 5)

Hunger refers to the physiologic sensation that is associated with the "drive to obtain food", and appetite encompasses a range of factors associated with eating behaviour such as desire for food and "selection of specific nutrients and tastes" (King et al 1997 p1076). Regardless of the terminology, both loss of hunger and appetite are associated with the anorexia of acute illness (Lennie 1999). The underlying mechanisms that result in anorexia are not fully understood. However, it is thought that acute illness activates inflammatory mediators that trigger a systemic inflammatory response (Richardson & Davidson 2003). These mediators, often referred to as pro-inflammatory cytokines, are produced by a number of cells including activated macrophages and lymphocytes (Plata-Salaman 1989). Cytokines affect central nervous system controls of food intake (Lennie 1999). One of the best described pro-inflammatory cytokines is interleukin 1β which is known to exert a profound depression of appetite mechanisms (Maier et al 1998).

7.3.1.2 Early satiety

In addition to loss of appetite and hunger, there were other physiological changes that impacted on eating. Patients were conscious of feeling full after eating small amounts of food. One patient described this as: "*I order it, it looks nice on paper, I order it, it comes up, I sit and think that looks nice. One spoonful and I've had enough*" (Patient 15).

This feeling of fullness after a small amount of food, or early satiety is a common finding in acute illness (Plata-Salaman 1996). Cytokines have again been implicated in this process as interleukin 1β is known to stimulate the release of cholecystokinin (Daun & McCarthy 1998). Cholecystokinin is a neuropeptide that is secreted by the

small intestine with feeding. It binds to receptors on the gastric vagus which stimulate the part of the brain that controls food intake (Hameed et al 2009). This results in a reduction in food intake due to feeling full with increased levels of cholecystokinin being associated with greater satiety (Moss et al 2011).

In addition to influencing satiety during a meal, cytokines also affect the initiation of subsequent meals (Lennie 1999). Tumor necrosis factor alpha (TNFα) is thought to suppress vago-vagal reflex circuits in the hypothalamus which results in delayed gastric emptying (Hermann & Rogers 1995). This feeling of fullness increases the length of time before hunger is felt (Richardson & Davidson 2003).

7.3.1.3 Taste changes

Patients reported taste changes, particularly noted during the first few days of transfer to the ward. Some patients described food as being bland, some reported that food tasted salty and others experienced a 'metallicky' taste when eating. These taste changes were most apparent when relatives brought in a previously enjoyed food and this was found to be unpalatable. These taste changes were noted to cause food aversions and changes in food preferences. Some patients avoided coffee as it tasted bitter, others avoided soups and pasta dishes as they found them too salty and many reported non-specific taste changes which resulted in foods tasting different from the way they were previously experienced.

Taste changes have been reported in other patient groups, one study looking at taste changes in patients undergoing cancer chemotherapy found coffee, tea, chocolate, citrus fruit and red meat were commonly avoided due to taste changes (Holmes 1993). Another study looking at food preferences of renal dialysis patients found that red meat was not well tolerated (Dobell et al 1993). Although the patients in this study did not specifically mention an aversion to red meat, the author speculates as to whether this could partially account for the lower protein intakes in comparison to calorie intakes. This is supported by work from Winograd and Brown (1990) who reported that sick patients showed a preference for high calorie, low protein foods. Evidence from animal studies indicates that this preference for high calorie, low

protein foods may be attributed to increased levels of pro-inflammatory cytokines (MacDonald et al 1995).

7.3.1.4 Nausea and vomiting

Patients reported problems with nausea and vomiting, particularly those receiving enteral feeds. This patient group had the most complex on-going medical problems during their ward stay and it was difficult to ascertain if the nausea and vomiting was a result of their medical issues, drug therapy, enteral nutrition or a combination of all three. Nutritional intake was compromised as enteral feeds were stopped or the rate was reduced when patients experienced nausea or vomiting. There was also a reluctance to eat when these physiological symptoms were present. The effect of nausea and vomiting on nutritional intake has been well documented in cancer patients and is associated with weight loss in this patient group (Huhmann & Cunningham 2005).

7.3.1.5 Pain

The presence of pain was reported by patients, especially those who had on-going surgical complications. Although patients did not directly associate pain with a reduced food intake, it was apparent that pain served as a powerful distraction. Patients who were in pain were observed to eat very little food at mealtimes. The association between pain and reduced nutritional intake has been demonstrated in a study by Paillaud et al (2003). The study explored the factors which affected prognosis in 71 patients with advanced cancer. Results showed that the presence of inflammation and a reduced energy intake were associated with a poor prognosis. Energy intakes were found to be inversely correlated with pain scores and the authors concluded that improving pain control would facilitate an increased nutritional intake.

7.3.1.6 Altered sleeping patterns

Patients reported changes to their sleeping patterns, commonly waking at night and sleeping for periods during the day. Sleep-related problems after ICU are well recognised and can persist for a considerable length of time (Orwelius et al 2008).

Sleep disturbances were observed to have a detrimental effect on nutritional intake. Patients often slept late in the morning as they had been awake for periods during the night and therefore missed breakfast. Increased daytime sleeping patterns also meant that patients failed to consume prescribed supplements and snacks as they were often asleep between meals.

The result of all these physiological changes for the post ICU patient was that eating ceased being a pleasure, something that was previously anticipated and enjoyed. It became a chore, something that had to be done out of necessity to fuel the body. This quote is representative of the majority view.

"*I'm eating because I have to..... I'm eating because it is necessary to live, to eat. You've got to get your dietary stuff, your nutrition, all the stuff you need to get by in life but it's a struggle now.*" (Patient 16)

It is therefore unsurprising that patients struggled to meet their nutritional requirements. The researcher argues that patients need to make a connection between the importance of food in promoting recovery in order to eat, instead of simply responding to the usual physiological triggers that prompt food intake. These physiological factors provide a powerful disincentive to eating. To overcome this, the patient would require an understanding of what is going on in order to make a conscious decision to choose to eat even when they have no desire to do so. It also challenges the traditional dietetic approach of prescribing oral nutritional supplements to ameliorate the calorie deficit without addressing the underlying problem.

The physiological changes experienced by the patient as part of their dysfunctional body were compounded by the inability of the organisation to respond and manage these problems. Hence the categories 'experiencing a dysfunctional body' and 'encountering nutritional care delivery failures' were interrelated. It was evident from the data that patients who were experiencing early satiety struggled with hospital meals that were provided three times a day as they only managed small amounts of food at each meal and yet these meals were only available thrice daily.

Lack of flexibility in relation to the timing of meals meant that patients with altered sleeping patterns often missed meals or found that no food was available during the periods they were awake. This is a specific example of policy that is not 'patient centred' for this patient group and has a detrimental effect on nutritional intake.

Patients who had a poor appetite found that having three courses served at one time provided a disincentive to eating. The size of the meals was also found to be off putting for patients with reduced appetites. The influence of appetite on portion sizes was highlighted in a study of older patients in an acute care setting by Xia and McCutcheon (2006) where patients with poor appetites reported that big portion sizes were unappealing. The current study also highlighted that patients experiencing taste alterations, another physiological aspect of the dysfunctional body, found that their food preferences changed and limited menu choices made this difficult to accommodate. The researcher argues that the combined effect of the highlighted physiological changes coupled with the associated organisational constraints serves to limit nutritional intakes in the post ICU patient.

7.3.2 Facing psychological changes

Another element of the dysfunctional body was the identified psychological changes such as low mood, anxiety and delirium, all of which are well recognised complications of critical illness (Johns et al 2010a). The presence of delirium has been associated with poor nutritional intakes in a study by Mudge et al (2011). The current study supports this finding as patients suffering from ICU related delirium, a condition characterised by "*a fluctuating decline in attention, awareness and mental clarity, with disorganised thinking*" (Johns et al 2010a p547), were noted to have poor nutritional intakes. Again this was compounded by the inability of the organisation to respond and manage this. Patients were unable to recall what they had eaten, indeed if they had eaten, and did not ask for assistance at mealtimes. Patients were unaware of the need to ask for additional snacks and nutritional supplement drinks if these failed to be delivered. It was also noted that these patients were often in side rooms which limited observation of potential nutritional issues by healthcare staff.

Many patients experienced anxiety and low mood and were profoundly affected by their ICU experience as these quotes illustrate.

"*I'm having a struggle but I don't like people to see me down. I try and put up a front.*" (Patient 5)

"*(My mood) is up and down, it's up and down..... it's a mixture of frustration but also selfish and that's because I feel frustrated that I should be in so many ways, you know, counting my blessings.*" (Patient 4)

"*I just dinnae understand. I dinnae. I cannae come to grips with what's happened, where I have been. I don't know, I jist dinnae ken.*" (Patient 14)

It was clear that patients struggled to come to terms with all that had happened to them and cope with all the changes associated with critical illness; therefore, eating was not a high priority for them. Patients' anxieties stemmed from their ICU experience with many suffering from nightmares and flashbacks yet no explanation was provided about this from ward staff. Patients in the intervention group of the RECOVER study had a visit from an ICU consultant to discuss their ICU stay and highlight common ICU related problems. Part of the generic rehabilitation assistant's role was to provide psychological support and reassurance to the patient and screen for on-going psychological issues. The researcher argues that patients fail to make the link between the psychological changes they faced after ICU and a reduced food intake. Little was done to address these psychological issues from an organisational perspective and the GRA played a key role in dealing with many of the psychological concerns in the intervention group of patients from RECOVER. The beneficial influence of the GRA is illustrated in this quote:

"*I don't know what I would have done without her. She's been with me since the beginning (of patients ward stay) and supported me, talked things through with me and reassured me. She's a good woman."* (Patient 14)

The GRA provided continuity of care to patients and offered the physical and emotional support needed by this patient group. Interestingly, the GRA was described as a 'good woman'; a term used by Oakley (1984) in her classic paper which drew parallels with family and healthcare roles. The qualities of a 'good

woman' were described as being analogous to those of 'good nurse' (Oakley 1984). It is speculated that the role of the GRA in the doctoral study may have been fulfilling the role previously provided by nursing staff.

7.3.3 Dealing with changes to body, self and identity

All patients experienced bodily changes as a result of their ICU stay. The majority of patients reported that their bodies were weak and fatigued. Reduced functional ability is a well-recognised problem after ICU due to loss of muscle mass (Griffiths & Jones 1999), resulting in high levels of disability for this patient group (Barnato et al 2011). Patients became increasingly aware of their body after ICU with realisation often coming after experiencing its limitations. Their body was unable to do what they wanted it to do or indeed what it used to do. The quotes below illustrate these points demonstrating problems with reduced mobility, breathlessness and extreme fatigue.

"*I said oh my God I'm never going to be able to walk 'cause I had a couple of fly tries coming from here to this seat and I was lucky I never broke my neck.*" (Patient 3)

"*I'm still tired, still tired. I mean to walk from here to the toilet I'm exhausted.*" (Patient 15)

"*I wouldn't believe I could be so weak when I came out (of ICU). I really didn't believe it and yet you know, phew, it really was quite startling.*" (Patient 12)

"*I just get so breathless. I'm okay when I'm sitting down or lying down, but as soon as I have to move I just get very breathless.*" (Patient 5)

"*Just walking and being stronger and that. I feel like a two year old bairn. I walk to the toilet and I'm knackered.*" (Patient 7)

It was also apparent that although patients were immediately aware of the changes to their body after ICU, the extent of their bodily limitations were not fully realised until they went home. In the ward everyday tasks such as cooking and cleaning were taken care of, however when patients went home they had to do more for themselves. The quotes below illustrate this.

"*Oh I couldnae get up the stairs and that for days. I actually went to stay with my mum for the first couple of days, slept on my mums' couch cause I couldnae bend doon and pick up anything and that.*" (Patient 7)

"*When I came hame at first it was hard, it was hard..... In there (hospital) you've got everything done for you. You've got yer meals made for you and all that and when you come home, yae've got to do all that yerself.*" (Patient 14)

This discovery of a dysfunctional body is common in illness and pain (Van Manen 1998). Work by Bury (1982) noted that illness is an experience in which the "structures of everyday life and the forms of knowledge which underpin them are disrupted" (Bury 1982 p169). Since then this concept of 'biographical disruption' has been used in the study of certain illnesses, particularly chronic illness. The first aspect of this concept is disruption of taken for granted assumptions and behaviours. Illness brings attention to "*bodily states not normally brought into consciousness*" (Bury 1982 p169). The researcher argues that after critical illness patients rediscover a body which they were previously unaware of, as a result of its dysfunctional state.

As mentioned in Chapter 2, the focus of previous research has been around experiences of chronic illness which highlights the swing between states of 'dys-embodiment' and 're-embodiment' (Williams 1996). The researcher would argue that after critical illness, unlike the insidious nature of chronic disease, there is a sudden, profound change in bodily function as patients are often well prior to the events that led to ICU admission. Critical illness also results in bodily changes that cannot be prepared for and are often extreme compared to other types of illnesses. This may mean that patients' ability to move from the dys-embodied state to the re-embodied state, where they can reclaim a world where they accept their body the way it is, may be more difficult. In addition the researcher postulates that although adaption to bodily changes may start to occur in hospital, the process must start again after hospital discharge as the patient experiences new bodily limitations. The quotes below illustrate this.

"*Trying to get the housework done..... I'd maybe hoover and dust a room and I would just be too tired. I'd want to lie down.*" (Patient 6)

"*That's how I feel maist mornings. I work just to get up. I can't dae nothing. I cannae play football know what I mean. If I run for about 5 minutes I'm knackered.*" (Patient 7)

"*.....in the morning I have to go down the stairs sideways and up them one....., ken both feet at a time on the stair whereas throughout the day after three or four hours I can walk up and down them normally.*" (Patient 2)

When patients were discharged home they became aware of their bodily limitations when trying to carry out the activities and tasks that they previously were able to do. Daily activities such as getting out of bed, walking down the stairs and housework were difficult and patients had to learn to adapt to these restrictions for example by going down the stairs sideways or incorporating frequent rests when tackling household chores. Patients reported feeling frustrated, angry and upset during the process of adaption and questioned if their body would ever return to its previous level of function. It is speculated that this explains the increased scores from symptom based outcomes from the visual analogue scales where patients reported high levels of breathlessness and fatigue (Chapter 6).

7.3.3.1 Coming to terms with bodily changes - the impact on self

This dys-embodied state, typified by weakness, fatigue and impaired functional ability in the post ICU patient, disrupts the sense of unity between the body, self and identity (Charmaz 1995). Kelly and Field (1996) state that "*self is linked to body in so far as common-sensically self and body are experienced as one and the same thing. However when bodily demands conflict with desired self-presentation, the individual becomes acutely aware of the divergence between body and self*" (p245). Charmaz (1983) argues that loss of control leads to loss of self. This loss of control was experienced by post ICU patients and many expressed feelings of anxiety, stress, fear, concern, and frustration in relation to their altered bodies. The quotes below illustrate these feelings.

"..... *it's the sheer frustration as well, the sheer frustration of not being able to do what you want to do and obviously the tiredness is a contributory factor to that.*" (Patient 12)

"*I'm depressed in as much as I don't like not being well cause this is not a regular thing for me not to be well..... so that depresses me a bit and I get depressed because I cannae get up and go for a walk because I'm not physically up to it.*" (Patient 9)

"*One of the fears is will I ever get back to what I was?*" (Patient 15)

"*You know you take for granted you make a coffee, make a tea, you have a bit of cereal, you go to work or whatever and that's the way you expect to live your life and then when that gets interrupted..... There's a lot of people who have been in worse situations than me but it doesn't help.*" (Patient 4)

Patients also experienced loss of control over what their bodies were subjected to during their ward stay. Bodies were routinely stabbed for blood, examined by doctors and exposed to various tests and procedures. Bodies were also awoken, washed, repositioned, exercised and in some cases an artificial liquid formula was administered through a tube into it. Patients had limited control over many of these actions and one patient commented "*I feel like my body is not my own*" (Patient 14). The researcher argues that this loss of bodily control further compounds the loss of self, making it more difficult for the patient to adjust to their altered body.

7.3.3.2 Coming to terms with bodily changes - the impact on identity

Bodily appearance is intrinsically linked to social identity and illness can alter the way individuals are perceived by others (Kelly and Field 1996). This is particularly pertinent for the post ICU patient as the effects of critical illness can lead to quite dramatic changes to physical appearance as a result of weight loss and reduction in muscle mass.

Another reported physical change was related to the presence of enteral feeding tubes. Patients were acutely aware of the tube and the fact that it was visible to others, one patient called it her "*elephant nose*", another simply stated that she hated it and wanted it out. The obtrusiveness of the tube has been found to negatively impact on identity as it renders the person unable to "*present an ordinary version of self to the world*" (Kelly 1992 p403). This can result in a stigmatised identity as the visible presence of the tube means that the patient does not conform to societal

norms (Goffman 1963). Tubes were perceived as an 'abnormality' and patients were keen to have them removed as soon as possible.

Lupton (1996 p1) argues that "*food and eating are central to our sense of self and our experience of embodiment*". The researcher postulates that as body, self and identity are intrinsically linked, bodily disruption as a result of critical illness can disrupt the way patients relate to food. The meaning of 'you are what you eat' has evolved from being concerned with 'internal health of the body' to the 'external look of the body' (Germov & Williams 2008). In this sense, for the post ICU patient, critical illness has resulted in bodily changes both in terms of the functioning of the body and bodily appearance that were out with individual control. In order to restore the body, patients have to overcome the self's intrinsic regulation of food and relearn what to eat and how much. This is ultimately made more difficult because of the negative influence of the underlying physiological changes previously discussed. The majority of patients were aware of the need to eat to promote recovery as the quotes below illustrate.

"*Well I suppose it is like everything else. Its part of the bigger picture isn't it. If I don't get enough protein, carbohydrate, vitamins and what not then that's going to hinder my progress isn't it?*" (Patient 9)

"*I think eating is a very important factor (to recovery). It helps to get your energy and things like that to help you progress.*" (Patient 16)

However, there is a tension between patients' awareness of the importance of eating to promote recovery and intrinsic self-regulation of food. This regulation of food behaviour is a result of social and cultural influences and these will be discussed in the next section.

Patients also had to come to terms with changes to their physical appearance by realigning the body and self (Knudson-Cooper 1981). Negative reactions from other people, especially family members, lead to identity change which then have a detrimental impact on the self (Charmaz 1983). Wainwright et al (2007 p760) highlights that "*the process by which we make sense of physiological change through*

social interaction also influences the recovery of physical performance, including appetite and food consumption". Again it was found that the health care organisation failed to acknowledge or address the bodily changes experienced by patients after critical illness or the impact this had on the patient's sense of self and identity. The researcher argues that this would have a detrimental effect on physical recovery as patients clearly struggled to adjust to changes in physical appearance and function.

7.4 Summary of Section 1 Experiencing a dysfunctional body

This section reveals the complex relationship between food and the body. Critical illness disrupts the physiological and psychological functioning of the body and also alters the relationship between body, self and identity. Organisational failings meant that these bodily disruptions experienced by post ICU patients were not acknowledged or addressed and this ultimately had a detrimental effect on nutritional recovery.

Section 2 Experiencing socio-cultural changes in relation to eating

7.5 Introduction

This section examines the social-cultural aspects of eating and the influence of this on nutritional intake for post ICU patients. Food in hospital is often perceived as serving a biological purpose and Lupton (1996 p7) highlights that "*the very notion of nutrition is a health and functionally orientated one: food is for nourishing, for fuelling the body, for building bones, teeth and muscle, a means to an end. Food preferences, tastes and habits are considered secondary to what food does biologically to the body, important only in their shaping of what types of food enter the stomach*". The properties relating to this category are experiencing social isolation, struggling to adapt to an unfamiliar culture and the importance of food habits and routine (figure 48). Each one is discussed in turn below.

Figure 48: Properties relating to the category 'Experiencing socio-cultural changes in relation to eating'.

7.5 1 Experiencing social isolation

Over half of the patients in the study were discharged from ICU to a side room on a ward due to the presence of hospital acquired infections such as MRSA or Clostridium Difficile. Patients struggled with this imposed social isolation; one patient commented "*I don't think it's really good for me psychologically……..I'm quite a sociable person. I think it's not been maybe beneficial for me (being in a side room), that's why I like the door kept ajar, just to sort of……*" (Patient 5), another patient said "*I'm bored, I'm really bored*" (Patient 10). Many of these patients were initially bed or chair bound due to critical illness related muscle weakness and fatigue and were unable to leave the confines of their room. Meals were eaten alone in their room, often in bed. Social isolation was a contributory factor to reduced nutritional intake with patients perceiving meal times as much more than just for eating, they also provided opportunities for social interaction. The quotes below illustrate this.

"*I think being alone you don't eat as well as if you've got somebody with you.*"
(Patient 11)

"Eating with someone makes a difference because I like to yap, talk and talk."
(Patient 12)

"I think it's just the fact there is more than one of you makes it better." (Patient 4)

The social nature of eating is well recognised as "*almost all social interaction involves food and drink, not simply to fulfil a physiological need, but to affirm the social bonds we have with other human beings*" (Slomka 1995 p1259). The effects of social interaction on food consumption has also been well documented (de Castro & de Castro 1989, de Castro & Brewer 1992, Clendenen et al 1994). In a study of healthy individuals it was shown that eating with family or friends increased food intake by as much as 44% compared with eating alone (de Castro 1996). The influence of others on eating behaviour has also been shown in hospitalised patients. A study by Wright et al (2006) found energy intake was 36% greater in patients using a supervised dining room compared to those eating beside their bed.

Lupton (1996) highlighted the significance of meal times stating that "*the sharing of food is a vital part of kinship and friendship networks in all societies"* (p37). A small number of patients in the study were taken down to the hospital canteen by their relatives for meals. Patients reported increased nutritional intakes at these meals and derived pleasure from being taken out of the ward setting with eating perceived as a social activity.

7.5.2 Struggling to adapt to an unfamiliar culture

Social culture shapes what we eat and forms who we are (Germov and Williams 2008). Food is perceived as "*good or bad, masculine or feminine, powerful or weak, alive or dead, healthy or non-healthy, a comfort or a punishment, sophisticated or gauche, a sin or a virtue, animal or vegetable*" (Lupton 1996 p1-2). These culturally derived meanings of food influence food choice and defines who we are. Many patients in the study mentioned their pre-hospital choices of 'healthy foods' as the quotes below illustrate.

"*I always made sure I had something healthy for tea.*" (Patient 2)

"*I suppose we try to eat fairly healthily.*" (Patient 12)

"*It was a fairly balanced diet, maybe not enough vegetables but I make up for it in fruits and things like that.*" (Patient 10)

These views reflect socio-cultural influences in advocating a healthy diet and the majority of patients highlighted their previous orientation towards healthy choices. The three patients who were the exception had a documented alcohol dependency. These patients reported erratic eating patterns, often just eating one meal a day and this usually comprised of a ready meal or fast food.

In contrast, hospital culture dictates that food is non-individualised and is provided as a medical treatment (Ferrie 2010). Hospital food is provided for its nutritional properties with a focus on the biological need for nutrients i.e. 'functional meal provision', not the culturally derived food preferences or choices evident in meals provided at home (Batstone 1983). The nutritional content of hospital meals is stipulated by national standards. In the study hospital the meals are out sourced, mass produced and delivered in bulk therefore there is little scope for individual variation.

For the post ICU patient who has often lost significant amounts of weight as a result of the catabolic effects of critical illness, the focus of dietetic interventions is to promote the consumption of high calorie, high protein foods to replenish nutritional stores and facilitate weight gain. Scrinis (2008) termed this approach where food is viewed solely in terms of its nutritional composition as 'nutritional reductionism'. The inherent danger with this is that it "*encourages us to disregard whatever sensual, aesthetic, cultural and environmental reasons we have for our food choices and to focus only on our bodies' needs for individual nutrients*"(Ferrie 2010 p439). The researcher, as a practising clinical dietitian, recognises that this approach involves the patient having to override previous culturally derived food choices, necessitating an adjustment to self, in order to accommodate new eating practices. These changes to self are compounded by the fact that the patient is already experiencing a dysfunctional body and dealing with changes to body, self and identity associated with altered physical appearance and functioning.

7.5.3 Importance of food habits and routine

Patients highlighted the importance of familiar foods and routine in promoting nutritional intake. It was apparent that meals made from ingredients of choice, prepared the way they wanted it and provided when they were ready to eat were conducive to enjoying eating and augmenting food intake. Meals at home were contrasted with those provided in hospital. The quotes below illustrate this:

"I suppose you get used to a certain type of food that you have at home and how it was done. I mean something like an egg, some people like it hard boiled and some soft and ken it's just your own habits." (Patient 3 wife)

".....at home you feel you can do, you can eat when you want and if you feel like eating you know in-between, you know having a wee bit more often, small meals a bit more often." (Patient 15)

"I think that's 'cause it's home food you know and times as well.....you know I had said this to you before, that you know having my lunch at 12 o' clock and my dinner at 5.....I've had too many years of psyche where that hasn't applied, you couldn't just change that around." (Patient 4)

In hospital food is often prepared differently to habitual preferences with restricted food choices and timing of meals. Ferrie (2010) argues that the hospital exerts institutional power by controlling the timing and content of meals. However, it has been demonstrated that when patients are ill they often choose food that reminds them of home (Waters 2007) and giving patients some control over the type and timing of meals has led to an improvement in nutritional intakes (Holmes 1998). Many patients in this study had additional snacks, and sometimes meals brought in for them by relatives, food that was familiar to them and food that they previously enjoyed. Observations also showed that some patients overcame the problem of timing of meals by getting relatives to bring food from the canteen at a time that was more suited to their usual meal patterns.

The importance of food habits and routine is evident from their link with identity (Bisogni et al 2002) as behavioural patterns can comprise the "*individual's world, lifestyle and even identity*" (Zisberg et al 2007 p446). Patients described their individual identities incorporating different facets of eating related behaviour. One

patient described himself as a "*meat and potatoes man*", another reported that he "*ate anything, usually too much of it*" with one patient defining herself as a "*snacker who just grazes throughout the day*". Other examples included "*a small eater*", "*an irregular eater*" and a "*three meals a day type person*". Bisogni et al (2002) defined different types of identities relating to eating including identities relating to eating practices; personal attributes and social groupings. As individual eating patterns reflect who that person is i.e. their identity, self which is connected to habitual ways of seeing one's self can be threatened by trying to alter behavioural patterns (Charmaz 2002). This relationship between identity and different aspects of food and eating may contribute to our understanding of why eating routines are difficult to change (Jastran et al 2009).

Another dimension related to identity is the concept of "we are what we eat". Fischler (1988) argued in the act of eating we take on some of the foods characteristics and "*we become what we eat. Incorporation is the basis of identity*" (Fischler 1988 p279). If this theory is applied to the hospital diet then it could help to explain why patients are reluctant to eat foods that are unfamiliar to them as "*if we do not know what we eat, how can we know what we are*?" (Fischler 1988 p282). In the current study patients highlighted that the hospital menu contained food choices that would not normally be eaten at home, some dishes were unfamiliar to patients and these were avoided. The researcher argues that for the post ICU patient, who is already experiencing a dysfunctional body and related changes to self and identity, familiar food and routine is important as it helps the patient regain who and what they are. However, in hospital where food provision is not specific to an individual's culture, habits or routine, this may make it more difficult for the patient to restore their sense of self and identity.

Foods brought in from outside the hospital by family was found to be one way that helped restore the patients' sense of self and identity. This food is individualised and accommodates the patient's specific habits, preferences and tastes. The researcher argues that the provision of this food provides more than just calories and protein for

the patient, it also conveys a sense of nurturing, feeling cared for and loved and it touched the emotions, the self. The quotes below illustrate this.

"*We were bringing in things to tantalise his appetite, things that we thought he would like. Likes of we started bringing him in milk....., rice pudding, yoghurts and you know likes of what he was partial to oatcakes, and my daughter made banana bread.*" (Patient 15 wife)

"*It's my sister. I mean she can what we call 'bake for Scotland.' She's a marvellous baker so she's making sure I'm taking what I'm supposed to.*" (Patient 3)

"*My wife brings in cocoa every afternoon and sometimes if she'd been baking she would take in a slice of Belgian loaf and our daughter would bring in shortbread, things like that. I've got a fantastic family and I think that is a big help.*" (Patient 10)

The food brought in by families took on a symbolic meaning and conveyed a sense of nurturing. In hospital, where it is argued that "*feeding is a medical treatment, stripped of its cultural connotations and sensory pleasures*" (Ferrie 2010 p441) the food brought in by families is particularly significant as it offers all that the functional hospital food does not.

The researcher also argues that food became an outlet for relatives to be able to demonstrate love and provide care, even in a small way, after experiencing feelings of helplessness when the patient was in ICU. Food was given as a gift which is part of a caring relationship, as a way of demonstrating love. This food was prepared with the person in mind and their individual preferences taken into account. This concept of gift giving was highlighted in Titmuss's (1970) seminal book 'The Gift Relationship' in which he argues that blood donation is an act of altruism and can be treated as a gift. The meaning of altruism varies in the literature and includes both unconditional and reciprocal acts of giving (Rapport & Maggs 2002). Smith (1995) highlighted that altruism incorporates four attributes: "*a sense of personal responsibility for another's well-being,…a sense of compassion for another,…a sense of empathy and an uncalculated selfless commitment to the needs of others*" (p787). The researcher argues that these attributes of altruism were displayed by family members when giving their gift of food to the patient. On one hand the gift giver was motivated to provide food out of concern and a desire to help their relative,

however by taking on the responsibility for providing food a certain level of reciprocity was expected from the patient. The relative anticipated that the patient would eat the food provided and conflict arose if this was not the case as this quote illustrates:

"I think we were all on top of him. Everybody was 'you have to eat, you have to eat', you know the family ……..I think at that stage you were starting to get quite annoyed and we were getting annoyed." (Patient 15 wife)

This led to patients feeling pressurised to eat the snacks that were brought in and relatives became increasingly frustrated that the food was not being consumed. Family members had limited appreciation of the on-going problems faced by patients after critical illness with one patient stating "*They (family) dinnae understand why I'm still so tired and weak*" (Patient 15). Families are provided with relevant information about the patient's condition while they are in ICU, however little detail is given about the long term problems that patients may experience after critical illness.

7.6 Summary of Section 2 Experiencing socio-cultural changes in relation to eating

This section highlights the socio-cultural influences on food intake in patients after critical illness. The effects of social isolation, cultural and food habit changes also impact on the body, self and identity. Similarly, socio-cultural changes in relation to eating were compounded by organisational failings and adversely affected nutritional recovery.

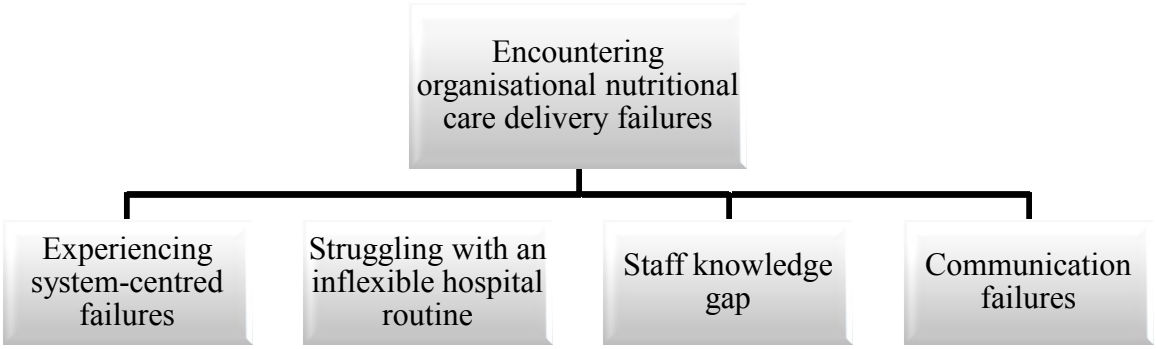
Section 3 Encountering organisational nutritional care delivery failures

7.7 Introduction

This section examines the third category that emerged from the data: encountering organisational nutritional care delivery failures. Nutritional care is a broad term that

can encompass many different elements. For the purposes of this study it is defined as ' *a co-ordinated approach to the delivery of food and fluid by different health professionals, and views the patient as an individual with needs and preferences. It is the process that determines a person's preferences and cultural needs, defines his or her physical requirements, and then provides the person with what is needed. It follows a person's progress through an illness, by responding to changing nutritional requirements. It involves the monitoring and reassessment of nutritional status at regular intervals, referral for specialist care when appropriate, and good communication with services in the community. Good nutritional care will involve training for staff, carers and patients, and access to information*' (NHS QIS 2003 p17). The properties relating to the category encountering organisational nutritional care delivery failures are: experiencing system centred failures, struggling with an inflexible hospital routine, communication failures and staff knowledge gap (figure 49).

Figure 49: Properties relating to the category 'Encountering organisational nutritional care delivery failures'.



7.7.1 Experiencing system centred failures

7.7.1.1 Poorly co-ordinated transitions in care

Observation of current practice demonstrated that limited nutritional documentation was provided on transfer from ICU to the ward. An ICU discharge summary sheet is completed by medical and nursing staff before the patient is transferred to the ward.

There is a nutritional section on the discharge summary with a tick box format where the appropriate box should be ticked that pertained to the current route for nutrition e.g. oral, enteral or parenteral. An additional space was provided to give details of the type and amount of artificial nutrition. However, it was noted by the researcher that the nutritional section was often left blank unless it was completed by the ICU dietitian. This summary sheet was filed in the medical notes and was not noted to be referred to at any point during the researcher's observations.

The ICU nurse also verbally handed over to ward staff the current route for nutrition and if the patient had commenced on oral intake. Observations showed that many of these handovers were pressured due to time constraints, were frequently interrupted and this often resulted in a limited exchange of information. Studies have highlighted that one of the 'pivotal' factors to a successful transfer is effective communication and the need for clear, concise documentation is crucial in this process (Whittaker & Ball 2000).

The researcher argues that with the number of complex issues experienced by this patient group, the priority of care on the ward is to initially address the most potentially life threatening problems. This means that nutritional issues are often overlooked during the early stages of ward care and delays were noted in reconnecting enteral feeds and recommencing nutritional supplements.

A verbal nutritional handover by the ICU dietitian to the relevant ward dietitian was provided. There was no systematic format to the handover but it would usually include an estimation of the patient's nutritional requirements, current route of nutrition and the type and amount of any artificial nutrition. Details would be provided of any oral intake, including nutritional supplements and any other relevant issues including loss of appetite, nausea and swallowing problems. However, none of the above mentioned processes identified a clear nutritional plan as recommended by NICE (2009).

Hospital discharges were also observed to be poorly co-ordinated in relation to information giving and organisation of on-going nutritional care. Since only 10 out of the 17 patients in the study had been followed up by a dietitian on the ward, the remaining 7 patients would not have received any nutritional advice on discharge from hospital. Six patients were discharged home with a supply of nutritional supplement drinks and advised to continue taking these at home. The three month interview data suggested that patients were not following the recommendations from the hospital dietitian with some taking fewer nutritional supplement drinks than advised and others were unsure about how many they should be consuming. The quotes below illustrate this.

"*He's no been taking them (supplement drinks)."* (Patient 3 wife)

"*We were doing two (supplement drinks) a day and we dropped off to one a day.*" (Patient 4 wife)

"*I take it (supplement drink) sometimes.*" (Patient 14)

Patient 3 had been advised to take one Fortisip drink, a high calorie milk-based nutritional supplement, and 40mls of Calogen 3 times daily, however he told the researcher that he stopped drinking them in the first week he was discharged home. Patient 4 was advised to have 2 Fortisips daily but by the three month interview he was only having one a day. Patient 14 was recommended to have 40mls of Calogen 3 times daily but informed the researcher at the three month post ICU discharge interview she only took them when she felt she wasn't eating enough. All five patients who had been advised to continue taking nutritional supplements at home were referred to community dietetic services for follow up. It was evident from the three month post ICU discharge interviews that none of the patients in the study had seen a dietitian since discharge from hospital. Financial constraints have led to a reduction in community dietetic services resulting in longer waiting times. A prioritisation system for community dietetic referrals has also been instigated. The findings from the study have demonstrated that despite the complex nutritional needs

of post ICU patients, they have not been allocated a high priority code which would allow a more urgent review.

Four patients asked the researcher, whom they knew to be a clinical dietitian, for advice about their nutritional intake during the three month post ICU interview. The information requested included advice about foods that were high in protein, suggestions for high calorie snacks, explanation about on-going taste changes and ways to promote weight gain. The researcher felt a professional responsibility to give therapeutic advice to a few of the patients who continued to struggle nutritionally.

Patients did not receive appropriate nutritional advice on discharge from hospital as evident from the lack of clarity surrounding continuation of nutritional supplements and the numerous requests for additional nutritional information from the researcher at the three month interviews. This highlights the need for a shift from service based dietetic management, to patient based management, as described in Chapter 6. Currently, patients are seen by a variety of different hospital dietitians depending on the area of speciality in secondary care facilities and a community dietitian in primary care. A patient based approach would allow continuity of care where the same dietitian could follow the patient from ICU to the ward and then into the community.

7.7.1.2 Influence of ward culture

It is postulated that lack of a clearly identified nutritional plan compounded with the noted influences of ward culture was responsible for the subsequent alterations to nutritional care. Observation of ward practice demonstrated that the general ward ethos was to remove any lines, tubes and catheters as soon as possible. This was reflected in the number of nasogastric (ng) tubes that were removed within the first 48 hours of the patient arriving on the ward. Of the 17 patients in the study, 9 were transferred to the ward with a ng tube in-situ with 6 of the these tubes removed within 48 hours of arrival on the ward on the advice of medical staff.

Differences were noted however between medical and surgical wards. The three patients who were transferred to surgical wards with ng tubes had their feeding tubes in situ until nutritional intake was sufficient to allow removal of the tubes. In comparison, all six patients who were transferred to the medical wards with ng tubes had their tubes removed within the first 48hours of admission to the ward prior to any formal assessment of nutritional intake.

The researcher postulated that these differences may be due to the fact that the surgical speciality is upper gastrointestinal and hepatobiliary surgery and the surgeons are more aware of the nutritional problems faced by this patient population. This could not be corroborated with current research findings as a recent study looking at the nutritional knowledge of surgical trainees in the UK demonstrated a lack of awareness of the basic principles of nutritional support (Awad et al 2010). The findings were no different from a study by Nightingale and Reeves (1999) who looked at the nutritional knowledge of clinicians in non-surgical specialities.

Another explanation for the differences in nutritional practice could be that all three patients who were transferred to the surgical ward on ng feeds were in the intervention group of the RECOVER study. In comparison, only one out of the six patients who were transferred from to the medical wards with an ng tube in situ was in the intervention group. It is also worth noting that this intervention patient was transferred to the ward over the weekend. The decision by medical staff to remove the ng tube was made over the weekend and these days are not covered by the generic assistant. The researcher argues that the presence and input from the generic rehabilitation assistant (GRA) had a positive influence on the patients' nutritional care as the intervention patients had a higher mean percentage calorie intake in hospital compared with the control group (Chapter 6). The GRA provided regular information regarding the patients' oral intake and highlighted any nutritional issues or concerns to the nursing and dietetic staff. This resulted in the patients continuing on enteral nutrition until their oral intake had improved sufficiently to allow discontinuation of the ng feed. The potential benefits of a GRA will be discussed in more detail in section 4 of this chapter.

For the six medical patients who had their ng tubes removed on the ward, no clear rationale for the removal of these tubes was provided in the medical notes. One patient's tube was removed with no record of this found in the medical notes. For the other five patients who had their tube removed on the ward the entries in the medical notes by medical staff that related to this included: 'ng feed stopped to allow diet to grow', 'ng out, push full diet' 'encourage eating and drinking, ng out, 'ng out' and 'ng tube removed as eating and drinking well'. It was apparent medical staff thought that stopping enteral nutrition would lead to an increased oral intake. A brief interview with a junior doctor on the respiratory ward confirmed this as she said "*The tube was removed to allow him to eat more*" (FY2 doctor). Details of the patients' food intake from the study do not support this rationale and it was clearly demonstrated that they failed to meet their nutritional requirements after the ng tubes were removed. In reality it was shown that oral intake was minimal after the tube was removed. In some cases patients failed to meet their nutritional requirements for the remainder of their ward stay.

The other documented reason for removal of the ng tube was that the patient was eating well. It was not clear what constituted 'eating well' or indeed what information led to this decision. None of the patients had been reviewed by a dietitian prior to removal of the ng tube so the researcher postulates that medical staff were informed by the nursing staff or the patient as to the nutritional adequacy of the diet. Evidence suggests that post ICU patients consume less than 50% of their nutritional requirements in the first week after extubation (Peterson et al 2010). Therefore the researcher argues that it was unlikely that the patients in the study would have met their nutritional requirements orally, particularly during the initial few days on the ward.

Compounding this problem was the number of transfers from ICU outwith normal working hours due to bed pressures within the ICU. Eight of the seventeen patients in the study were transferred during the night. This meant that it was often junior medical staff making the decision to remove tubes and there was no dietetic presence to prevent this from happening. It is well recognised that out of hours transfers from

ICU are associated with a poorer outcome than those discharged during the day (Goldfrad & Rowan 2000). The rationale for the deleterious effects of night transfers include: reduced time for the patient to adjust to leaving the ICU, poorer quality medical and nursing handovers due to the pressured nature of the discharge, reduced staffing levels at night and no available support from multidisciplinary team such as a physiotherapist or dietitian (Carr 2002).

7.7.1.3 Impact of fragmented care

Pressure on acute care beds has meant that patients are discharged from hospital as early as possible. In this study the median length of ward stay was 10 days with a number of patients being discharged home within a week of being transferred to the ward from ICU. Nutritional intake on discharge from hospital for the 9 patients who had a ward stay of less than 10 days was inadequate as none of the patients met their estimated nutritional requirements at the time of hospital discharge. Seven out of the seventeen patients in the study were not reviewed on the ward by a dietitian despite their nutritional care being handed over from the ICU dietitian at time of transfer from ICU. Six out of the 7 patients were well-nourished on discharge from ICU, 1 was patient was malnourished. These patients would have received no nutritional intervention during their ward stay or nutritional advice on discharge from hospital nor any organised follow-up by community dietetic services.

The remaining two patients with a ward stay of less than 10 days were reviewed by a ward dietitian. One patient was commenced on oral nutritional supplements and subsequently advised to continue on these at home. The second patient, who had been advised on an initial visit by the dietitian to have snacks between meals, was discharged home without any subsequent nutritional advice. By three months post ICU discharge neither patient had been reviewed by a community dietitian since discharge from hospital. The researcher, as a clinical dietitian, felt a professional responsibility to offer therapeutic advice to one patient as they clearly had on-going nutritional issues.

It is interesting to note that the 8 patients who had ward stays of greater than 10 days were all reviewed by the ward dietitian. The researcher argues that as health service cuts have reduced dietetic staffing levels, this has led to the introduction of a dietetic priority referral system. As previously described, patients receiving artificial nutritional support are given higher priority than those on oral diet and length of time before review has increased. It is likely that these shorter stay post ICU patients were prioritised out as higher priority referrals took precedence.

Previous research has suggested that the prevalence of malnutrition correlates with length of hospital stay (Caccialanza et al 2010). In this study the nutritional status of 1274 patients was assessed on admission to hospital and patients were followed up for the duration of their hospital stay. They found that deteriorating nutritional status was associated with a prolonged hospital stay. However, a study by Naithani et al (2008) that looked at patients' experiences of access to food in hospital demonstrated that short stay patients (less than 2 weeks) experienced more problems relating to nutritional intake compared with long stay patients (longer than a month). The rationale for this was that long stay patients may have learnt adaptive behaviours and were better placed to cope with the issues relating to food than those patients who had a short hospital stay. Another potential explanation was that relatives offered support and assistance with food.

7.7.1.4 Problems with supplement and snack delivery

Other failings of the systems based approach identified in this study were problems in the delivery of nutritional supplements and snacks. As described in Chapter 5 the system is fraught with pitfalls as there are numerous stages involved in the delivery of the nutritional supplements/snacks from the kitchen to the ward. The quotes below illustrate this.

"*..... they are not brought up. I forget about it. I forget to ask for them.*"
(Patient 4)

"*I'm meant to be taking one a day..... but it's a case of you know you've got to ask the nurses and of course they are so busy doing..... if they remember to , you know*

you've got to keep saying are you remembering so they're probably thinking what a pain." (Patient 5)

"*I've no had them (snacks) since Sunday 'cause they said 'Have you had your cheese and crackers?' and I goes 'I'm wanting scone and jam.' They says, 'Right I'll go away and get you it' and never came back and I've no had any snacks since then.*" (Patient 2)

This identified system failure resulted in reduced nutritional intakes in patients who were already nutritionally compromised. Post ICU patients commonly suffer from cognitive impairment, specifically impaired short term memory and ICU related delirium, a condition characterised by "*a fluctuating decline in attention, awareness and mental clarity, with disorganised thinking*" (Johns et al 2010a p547) and may struggle to remember to ask for supplements or snacks. Delirium is relatively common after ICU although it is often under-reported and transfer to a new environment after discharge from ICU is a recognised causal factor (Johns et al 2010a). The researcher argues that this early ward period is when the physiological changes associated with critical illness are most prevalent, nutritional intake is at its lowest and there is the greatest need for supplements and snacks to aid calorie and protein intake. A service delivery model that relies on patients requesting nutritional supplements or snacks is inherently not patient centred or designed for this patient group.

7.7.1.5 Poor identification of nutritional problems

As detailed in Chapter 6, the quantitative results from the study demonstrated that the majority of patients consistently failed to achieve their nutritional requirements during their ward stay yet one of the striking observations from the nursing and medical notes was the general lack of documentation relating to nutrition. These findings were also demonstrated in a landmark study by McWhirter and Pennington (1994) who found that among the 200 cases of malnutrition reviewed, fewer than half had any nutritional information documented in the case notes. The authors concluded that the paucity of information relating to nutrition demonstrated on-going problems in the recognition of nutritional issues by healthcare professionals.

From the few instances where nutritional information was documented in the medical notes, comparisons were made with the food record charts that captured the patient's actual nutritional intake. Accounts from the notes such as '*eating well*' or '*good oral intake*' were not supported by the quantitative data. In addition it was noted tha,t for those patients who were under the care of the dietitian, there were often conflicting accounts in the notes from medical and nursing staff compared to that from the dietitian or the findings from the patient interviews. The quotes below illustrate this.

"*Had lunch, ng out.*" (Patient 4 Dr)

"*Managing small amounts of oral diet, recommend continuing overnight ng feed.*" (Patient 4 Dietitian)

"*Good oral intake.*" (Patient 3 Dr)

"*Only managing 50% of estimated nutritional requirements, recommend Fortisip supplement drinks tds.*" (Patient 3 Dietitian)

These were accounts from the medical notes relating to the nutritional intake of two patients; one comment was from the doctor, the other from the dietitian. In each case the nutritional accounts were documented in the medical notes on the same day. The researcher argues that these accounts from medical staff were accepted as fact and served to shape a nutritional picture about the patient that was not necessarily correct. These accounts were not obtained from a systematic approach to nutritional assessment; rather they were formed from a brief interaction with the patient, often by simply asking the patient how they were eating. The researcher argues that these findings suggest that medical staff lack nutritional knowledge. Parker et al (1992) identified doctors' poor nutritional knowledge 20 years ago with a report from the Kings Fund centre in the same year highlighting that doctors often failed to recognise malnutrition (Lennard-Jones 1992). The findings from this study suggest that, despite the recommendations from these previous reports to improve nutritional education, doctors still lack nutritional knowledge. This issue will be discussed in more detail later in the chapter under the heading 'staff knowledge gap'.

7.7.2 Struggling with an inflexible hospital routine

7.7.2.1 Limitations of food service times

Many patients highlighted issues around structured mealtimes and timing of hospital meals. Some patients were not accustomed to having three set meals a day as they were used to eating when they felt like it. Others struggled with having a main meal at lunch time as they were used to just having a light snack in the middle of the day. Another issue related to the timing of meals with patients reporting that they found breakfast very early and the evening meal also was served much earlier than they were accustomed to. The quotes below illustrate these points:

"*You know this sort of breakfast, lunch, supper, I mean that's just not for me you know. I sort of ate when I felt like it. But this regimental..... well it's far too early for breakfast but I force myself you know. Getting a cooked thing stuck in front of your face at 12 o'clock midday, it's just a, it's a struggle.*" (Patient 5)

"(My wife goes to the canteen) and I have my main meal at 6ish so I pushed it back and I found that a lot better..... (hospital meals are) the wrong time, you know I can't get my head around that you have your main meal at 5 o'clock. Now I understand the reasons why. I'm not stupid. They can't base their meal regimen around me. But it is a main part, it has a big impact on me." (Patient 4)

It is clear from these quotes that the timing of meals and the structured routine of meals in the hospital were detrimental not only to patients' nutritional intake, as some were not accustomed to eating at set meal times and others were used to having their meals at different times, but also to their emotional well-being. The role that hospital food plays in providing both physical and emotional support to patients during their hospital stay has been identified by Johns et al (2010b). Thus it was evident that hospital food was clearly failing to provide the necessary emotional support to those patients in the study that had expressed issues with timing of meals and meal structure.

Mealtimes are dictated by the organisation and are structured in order to facilitate hospital routine; however this system is not necessarily beneficial for the patient. Naithani et al (2008) identified meal serving times as an organisational barrier to eating in an observational study of hospital inpatients' experiences of access to food.

Patients reported that meals were served at times that were different to their usual routine and also commented on the lack of snacks available between meals which resulted in them feeling hungry, particularly in the evening as the evening meal was served so early. Another study by Kowanko et al (1999) demonstrated that nursing staff were aware of these issues yet failed to offer additional snacks.

For post ICU patients, who experienced a range of physiological factors as a result of critical illness (section 1), the issues relating to structured mealtimes and timing of hospital meals were particularly significant.

7.7.2.2 Problems with protected mealtimes

Protected mealtimes was an initiative introduced in 2004 as part of the Better Hospital Food Programme (DH 2004a). The purpose of a Protected Mealtime Policy is to create a time where all ward-based activities cease, provide an environment that is conducive to eating and releases staff to aid patients who need assistance at mealtimes (Hospital Caterers Association 2004). Davidson and Scholefield (2005) found that implementing a protected meal time policy improved mealtimes as there were fewer interruptions by relatives or healthcare professionals. However, the instigation of this policy has meant that visiting times are outwith mealtimes and this has implications for the social element of mealtimes (Taylor 2008). This interrelationship between organisational issues and socio-cultural influences on eating has been discussed in more detail in section 2 under the heading 'Experiencing social isolation'.

As relatives are excluded from visiting patients during mealtimes they are unable to provide assistance with eating or offer encouragement to aid intake. Family and friends are discouraged from providing meals prepared at home, as facilities for reheating food are often not available at ward level, and health and safety policies highlight the potential dangers of storing and reheating food on the ward. Limitations to food choices are imposed by hospital menus and this issue was compounded for some patients as they did not actually receive what they had ordered. Five out of the seventeen patients in the study had a ward stay of greater

than 21days. The hospital menu cycle is three weeks therefore for these patients food choices became even more restricted.

For the post ICU patient who may be severely debilitated as a result of critical illness, assistance with everyday tasks such as feeding may be required particularly during the early period on the ward. The researcher witnessed several conversations between nursing staff who were discussing the high level of care required for their post ICU patient and expressing their concerns that the patient was '*too dependent'* and '*lazy*'. Patients were also perceived as being '*demanding*' and '*precious*'.

The researcher argues that nurses' attitudes towards post ICU patients are constructed from negative stereotypes. Kelly and May (1982) suggested that patients are stereotyped depending on whether or not they conform to the demands made on them to facilitate the smooth running of the ward. Post ICU patients can be severely debilitated and it is speculated that as they have different needs to the typical short stay surgical patient, they are perceived as a disruptive influence on the ward.

The post ICU patient presents an additional conundrum as, although they require a high level of nursing care, they do not fit the classic scenario of a frail, elderly patient where, for example, the need to assist with feeding is well recognised (Campbell 1993, Wright et al 2008, Webster & Healy 2009). Half the patients in the study were of working age (18-65), the youngest being 20 years old, and this age group do not usually require assistance with eating.

Stereotyping has been found to exert self-fulfilling effects as patients' behaviour may be affected by nurses attitudes (Coudin & Alexopoulus 2010) and may also compromise nursing care (Courtney et al 2000). While this work was done in elderly patients the researcher argues that parallels can be drawn to the post ICU patient as both groups have complex needs that oppose a system operating with high levels of specialism and short hospital stays. Wade (1999) highlighted that stereotyping is fostered in situations that incur time pressures and workload demands. Lack of education has been identified as a precursor to stereotyping (McLafferty & Morrison

(2004). The researcher postulates that lack of education about the complex needs of post ICU patients may contribute to the negative attitudes of ward nursing staff. The study demonstrated the need to raise awareness of the complex needs of this group of patients who are cared for on the ward by staff who are not experts in dealing with the problems that follow critical illness. This educational need was reported by Carr (2002) who highlighted that a greater understanding of the physical and psychological problems faced by patients after ICU would allow ward nurses to provide more effective care.

In many cases the protected meal times policy has not been consistently adhered to and studies have demonstrated that patients still experience disruptions at mealtimes (DH 2007). This study supports these findings with patient accounts describing occasions where meals were interrupted or missed completely. Missed meals were as a result of the patient being off the ward for a clinical investigation or procedure, usually over lunch time. A study by Horan and Coad (2000) also identified the midday meal as the most commonly missed meal. This missed meal results in a loss of vital nutrition, particularly if the midday meal is the main meal of the day (O'Regan 2009).

7.7.3 Staff knowledge gap

Staff knowledge gap was another property that was related to the category ‘Encountering organisational nutritional care delivery failures'. Observations from the study demonstrated that there were a number of healthcare professionals involved in the nutritional care of patients including nurses, doctors, dietitians, clinical support workers and catering staff. Beck et al (2002) highlighted that a major barrier to optimal nutritional care was the ambiguity over responsibility for the specific elements of nutritional care.

It has been well documented that the nutritional knowledge and training of doctors is poor (Parker et al 1992) yet it was clear from the study that doctors were influencing the nutritional care of the post ICU patient. This lack of nutritional knowledge, particularly about the complex needs of the post ICU patient, resulted in enteral

nutrition being discontinued earlier than necessary, failure to identify on-going nutritional problems and incorrect information relating to nutritional intake being recorded in the medical notes. Identification of doctors' lack of nutritional knowledge led to a report from the Royal College of Physicians that highlighted the need to educate doctors in order to improve their recognition and management of nutritional problems (Royal College of Physicians 2002). However, despite the recommendations from the report, it is apparent that medical undergraduate training has not addressed this gap in education and doctors still fail to recognise the importance of nutrition in clinical practice.

Traditionally the responsibility for nutritional care has been a part of the nursing role and it is argued that nurses have a duty of care to ensure that patients receive adequate nutrition (Tolson et al 2002). However, nutritional responsibilities have evolved over time. This was apparent from observations of mealtimes in this study where clinical support workers were responsible for giving out and collecting the meal trays. The responsibility for food provision has conventionally been a nursing role (McInerney 1992), however in recent years this has largely been devolved to untrained staff (Xia & McCutcheon 2006). The rationale behind this change in practice was to release nursing staff from 'non-nursing tasks' to give precedence for more important nursing duties. This could have a negative impact on patients' nutritional care as nurses may be less aware of how much patients are eating at mealtimes (Kowanko & Simon 2001). The researcher argues that the disassociation of nurses with meal times also undermines the importance of nutritional care.

Since none of the seventeen patients in the study met their nutritional requirements during their ward stay it was clear that patients were not eating all of their meals. Lack of nursing awareness about food intake could result in patients becoming nutritionally compromised. This was clearly demonstrated in one patient in the study who had a four week ward stay and, although food charts kept by the researcher indicated that calorie intake was less than 40% of estimated nutritional requirements, no reference was made to this in the medical notes nor was the patient referred to the dietitian. The researcher postulates that lack of knowledge, specifically about the

post ICU patient, compounds the issue. The patient had a protracted ICU stay, had ongoing chronic medical problems and from his interviews described a number of 'classic' post ICU problems such as poor appetite, early satiety, taste changes, fatigue, disturbed sleep and low mood (Chapter 5).

Nurses' lack of nutritional knowledge has been previously identified in a number of studies (Kowanko et al 1999, Kondrup et al 2002) and similar to medical education, clinical nutrition has been afforded relatively little attention in the nurses' training curriculum (Bond 1998, Brogden 2004, Agnew 2005). The researcher argues that this study has demonstrated that nurses' nutritional knowledge is still lacking and this has had a negative impact on the provision of nutritional care.

The quantitative findings from this study have shown that despite dietetic interventions post ICU patients still failed to meet their nutritional requirements. Current dietetic practice for a patient requiring nutritional support involves calculation of individual requirements and comparing against nutritional intake. It is a time consuming and often difficult task as some patients are unable to recall what they have eaten, particularly if they are suffering from ICU related delirium. This then relies on accurate food record charts being kept by nursing staff. Bearing in mind so few patients actually met their nutritional requirements, the researcher questions whether it is worth the dietitian spending the time calculating requirements and intake.

Increasing pressure on dietetic time, due to staffing reductions, has necessitated instigating a priority system where patients requiring artificial nutrition are given top priority. Patients managing food orally are not necessarily seen as quickly or reviewed as frequently. Therefore, reducing seemingly ineffective interventions, such as calculating nutritional requirements and intake, would allow other approaches to be adopted. The findings from this doctoral study highlight that an individualised approach to nutritional management should be adopted in order to address the nutritional needs of post ICU patients. This is discussed in more detail in Chapter 8.

Findings from this study demonstrated that current dietetic interventions did not improve nutritional outcome in this patient group. This is supported by Peterson et al (2010) who demonstrated that there was no significant difference in the energy intakes of post ICU patients followed up by a dietitian compared to those who were not under dietetic care.

In some cases in this study interventions were shown to do more harm than good. Interview data highlighted that nutritional supplements were poorly tolerated and this often resulted in patients refusing to consume them. The choice of nutritional supplements is dictated primarily by which nutrition company is awarded the contract, based on competitive pricing. The supplements available from the particular company are taste tested by the dietitians and a selection of flavours chosen. At no point in the process are patient views and preferences taken into consideration. Therefore the availability of supplements and choice of flavours may not necessarily suit the specific needs of post ICU patients who are known to experience taste changes, early satiety and poor appetite (Herridge et al 2003).

Interview data also revealed that patients found that ng feeding to be an unpleasant experience and was associated with increased gastrointestinal symptoms as illustrated below:

".....it was that thing (nasogastric tube) that was making me sick, because I could feel it at the back of my throat." (Patient 14)

".....he couldn't get it over. He was gagging and I don't know if a lot of it at the time, whether it was psychological or what, but because he had the tube in I think he still felt it." (Patient 15 wife)

"*It (ng tube) fell out and then they just said leave it out and see how I go eating on my own..... I think it was actually making me sick.*" (Patient 17)

The researcher questions whether the continuation of enteral nutrition actually inhibited oral intake as patients struggled to eat with the ng tube in-situ. In addition it was noted that these negative experiences of enteral nutrition were associated with feelings of frustration and despair with one patient saying "*I cannae handle this*"

(Patient 14). This leads the researcher to question whether enteral nutrition was having a negative impact on the psychosocial recovery of these patients. The researcher speculates that the presence of the tube served as a constant reminder of their illness, the extent of their debilitation and a potentially protracted recovery. The presence of the tube also served to make them look different and may have impacted on the way they relate to food. This interrelation between organisational issues and the body was discussed in more detail in section 1 under the heading 'Coming to terms with bodily changes - the impact on self'.

Observations from the medical notes revealed that there was little communication between healthcare professionals. An example of this was medical staff documenting the fact that the feeding should be stopped and the tube removed despite a previous entry by the dietitian highlighting the patient's insufficient oral intake and recommending the continuation of enteral nutrition. This fragmented approach to care, with each health professional operating independently on the ward, does not appear to promote optimal nutritional care. Findings from a study by Thoresen et al (2008) highlighted that dietitians need to collaborate with doctors to raise awareness of nutritional issues and Ferrie and Allman-Farinelli (2011) reported on the benefits of a multidisciplinary team approach to nutritional care.

Current organisation of care within the hospital means that patients are transferred from ICU to their parent speciality. The setup of dietetic services means that patients on the ward will be seen by a dietitian who has expertise in that specialist area, for example surgery. For the post ICU patient however, the issues are complex and diverse and unlikely to be fully recognised by the ward dietitian. The researcher's recent discussion with dietetic students has confirmed that nutrition and dietetic courses cover nutrition in ICU in the curriculum and dietetic literature also contains sections pertaining to critical care nutrition yet little, if no information is available regarding post ICU nutritional rehabilitation. The researcher suggests that dietetic training and education needs to incorporate a more holistic approach to increase awareness of all the factors that can impact on nutritional care in the post ICU patient.

7.8 Summary of Section 3 Encountering organisational nutritional care delivery failures

Overall, the findings from the study suggest that despite the plethora of reports, guidelines and standards that have been written relating to the provision of nutritional care in hospitals, organisational care delivery failures continue to adversely affect patients' experiences of eating and their nutritional intakes. The identified issues include limited nutritional information during transitions in care; ward culture influencing early removal of feeding tubes; problems with timing and structure of hospital meals; system failures resulting in snacks and supplement drinks not being consumed by the patient and issues around healthcare staff roles and responsibilities for the provision of nutritional care. These organisational system breakdowns affected patients' experience of their body and the socio-cultural aspects of eating.

Section 4 The role of the GRA in improving system breakdowns during the nutritional recovery process

The findings led to a substantive theory which gives an in-depth understanding of patients' experiences of eating after critical illness. This theory implies that interrelated system breakdowns are responsible for the inadequate nutritional intakes revealed in this study. It is the interrelation of the three identified categories that compounds the nutritional problems faced by this patient group. In order to improve the nutritional recovery in patients after critical illness these system breakdowns need to be addressed and re-designed.

As previously described in Chapter 4, this doctoral study took place within the context of the RECOVER study. Although the nutritional component of the intervention was designed a priori, it was less developed than the physical therapy component. The specific role of the GRA in the nutritional recovery process was not clearly defined. Based on traditional dietetic practice, the role of the GRA in the RECOVER study included: nutritional screening on a weekly basis using MUST (Appendix 1); recording daily oral intake; ensuring the recommendations from the

dietitian were carried out e.g. the delivery of nutritional supplements and snacks to the patient.

Seven patients were recruited from the intervention group of the RECOVER study to elicit their experiences of eating after critical illness with the additional input from a GRA. Interestingly these patients rarely mentioned the GRA during their interviews. The researcher postulates that this was because the patients simply accepted their input as part of routine ward care.

Some of these system breakdowns identified in this doctoral study were addressed by the GRA's as part of their role. In particular, the GRA's dealt with organisational breakdowns affecting nutritional care such as encouraging, or if necessary, feeding the patient at mealtimes (although this was limited to lunchtimes due to working hours) and recording food intake. The GRA's would review the patient multiple times during the day and therefore provided a significant input to their nutritional care often knowing more than the nursing staff. One GRA commented "*Because he was in isolation they (nursing staff) didn't go into his room that often to speak to him so the nursing staff I spoke to said, 'Oh I've not had a lot to do with him' so I don't think they had an accurate picture of what he was eating*" (GRA 2).

Another organisational system breakdown which was improved by the GRA was by ensuring the delivery and consumption of nutritional supplements and snacks. The only reported problems from patients not receiving their supplements or snacks were from over the weekend as the GRA's only provided a Monday to Friday service. The quotes below illustrate this:

"*I asked on Sunday..... I goes, 'I'm wanting a scone and jam.' They (nurse) says, 'Right I'll go away and get you it' and never came back.*" (Patient 2)

"*They (nurse) never gave me it..... I dinnae get it (Calogen) the whole weekend."* (Patient 14)

As part of their remit the GRA's also referred patients with ongoing nutritional problems to the dietitian. The study showed that the GRA positively influenced

dietetic care with 5 out of the 7 patients in the intervention group being seen by the ward dietitian. The two patients who were not reviewed by a dietitian had a short ward stay of less than a week. Only 2 out of 7 patients were seen by the dietitian in the control group, with a further patient eventually re-referred due to ongoing problems. The 4 control patients were not seen by a ward dietitian due to limited resources and had been prioritised out from ongoing dietetic care.

Socio-cultural issues were also addressed by the GRA's as they brought up additional food from the canteen to suit the patients' individual preferences or took the patient to the hospital shop to buy food.

The GRA's were also able to help the patient come to terms with the physiological and psychological changes after critical illness. Using knowledge gained from an initial training programme the GRA's were able to explain to patients the common problems associated with critical illness. This facilitated the process of bodily adaption and the changes to self and identity.

The success of the GRA's role was the fact that they were able to provide continuity of care in a service which has a very fragmented approach to care. Previous research by the researcher and her colleague highlighted that these post ICU patients can be seen by numerous healthcare professionals, with a patient in a previous study being seen by 61 different members of staff during his time on the ward (Salisbury et al 2010). The GRA was the most consistent contact and patients developed close relationships with the GRA's often expressing problems and concerns to them. The GRA's were able to provide encouragement, reassurance and support, focusing on what was important to the patient to optimise their recovery.

It is speculated that the influence of the GRA on nutritional care was limited by the original design of the RECOVER study. It was based on traditional dietetic practice which emphasises assessment and prescriptive nutritional advice. The findings from this doctoral study highlight the need for individualised nutritional management of patients that identifies and effectively deals with the multiple factors that influence

nutritional intake in this patient group. This approach is discussed in more detail in the next chapter.

7.9 Summary of chapter

This chapter described the substantive theory that emerged from the data. 'Interrelated system breakdowns during the nutritional recovery process' emerged as the overarching core category that influenced patients' experiences of eating after critical illness and encompassed the categories 'experiencing a dysfunctional body', 'experiencing socio-cultural changes in relation to eating' and 'encountering organisational nutritional care delivery failures'. Concepts such as socio-cultural aspects of eating and organisational related nutritional issues are not new, however this work has identified connections and interrelations between these concepts and provided new insights into patients' experiences of eating after critical illness.

The final chapter highlights the identified nutritional issues in post ICU patients and presents a model of care to improve current management of nutrition for patients recovering from critical illness.

Chapter 8: The Way Forward

8.1 Overview of chapter

In this chapter the researcher proposes a number of recommendations to address the nutritional issues that have been highlighted in this study. Firstly the potential benefits from re-organising care to manage all post ICU patients on one ward are explored. Then a nutritional care strategy that would address the findings from the study, starting in the ICU through to discharge from hospital, is outlined. The latter part of the chapter identifies the implications of this study for education, policy and research.

8.2 Summary of research findings

This study has provided new insights into patients' experiences of eating after critical illness. It has highlighted a wide range of factors which influence nutritional intake in this patient group that emerged from three themes: experiencing a dysfunctional body, experiencing socio-cultural changes in relation to eating and encountering organisational nutritional care delivery failures. The connections and interrelations between the body, socio-cultural factors and organisational issues were discussed.

These issues need to be addressed in order to provide the effective nutritional care described by NHS QIS (2003) as *'a co-ordinated approach to the delivery of food and fluid by different health professionals, and views the patient as an individual with needs and preferences. It is the process that determines a person's preferences and cultural needs, defines his or her physical requirements, and then provides the person with what is needed. It follows a person's progress through an illness, by responding to changing nutritional requirements. It involves the monitoring and reassessment of nutritional status at regular intervals, referral for specialist care when appropriate, and good communication with services in the community. Good nutritional care will involve training for staff, carers and patients, and access to information*' (NHS QIS 2003 p17).

The next section will explore potential ways of reorganising the provision of ward care in order to address the complex nutritional needs of post ICU patients.

8.3 Potential for reorganising ward care for post ICU patients

With the increasing specialisation of medical practice and the resulting fragmentation of care, an acute hospital ward does not provide an ideal setting for dealing with the associated co-morbidities of post ICU patients. On-going care for this patient group is provided by parent specialties and patients become widely dispersed across hospital wards according to local service geography. Although suited to service management, the findings from this doctoral study have demonstrated that this approach has a number of nutritional implications for the post ICU patient:

- There is high risk of poor communication between health care teams which means that on-going nutritional problems may not be highlighted.
- Ward based practitioners have an inadequate understanding of the specific needs of post ICU patients which means that there is less awareness of the importance of nutrition in rehabilitation. Ward staff also lack the knowledge of individual patients' journeys.
- Post ICU rehabilitation is not co-ordinated with individual ward therapists working in isolation. This lack of multidisciplinary team working means that nutritional care is not tailored to the individual rehabilitation needs of the patient.

There are a number of different potential rehabilitation strategies that could be considered during the ward-phase of recovery after critical illness. These include:

- A roaming specialist team providing advice only to ward-based staff, in a similar manner to outreach teams (DH 2000b), but with a rehabilitation focus as has been trialled in stroke management (Kalra et al 2000).
- Management of all patients, following discharge from ICU, together on one ward as currently occurs in stroke units (Stroke Unit Trialists' Collaboration 2007).

Potentially a roaming specialist rehabilitation team providing treatment to post ICU patients on the ward could be considered. However, this approach has not been reported in other patient populations and there are a number of issues that would

need to be addressed. The logistics of incorporating such a team to work with the established ward-based staff would be challenging. It is also envisaged that there would be problems delineating the responsibility of issues such as discharge planning. The funding source could also be difficult to identify due to the many areas of the hospital to which patients are discharged after critical illness.

8.3.1 Potential for reorganising ward care - experiences from the stroke unit

One speciality which has established a comprehensive, holistic model to provide an appropriate care environment for their patients is stroke medicine. Historically the care of stroke patients was provided by a variety of specialities including general medicine, neurology or medicine for the elderly. Stroke patients were therefore managed in a number of wards amongst a variety of other patients. For the last 20 years patients have been cared for in stroke units where there is a multidisciplinary team who specialise in stroke management (Stroke Unit Trialists Collaboration 1997).

The benefits of stroke units are well documented in the literature with a Cochrane review concluding that "*stroke patients who receive organised inpatient care are more likely to be alive, independent, and living at home one year after the stroke*" (Stroke Unit Trialists Collaboration 2007 p2). Little research has evaluated the components of stroke unit care that are necessary to improve patient outcomes (Langhorne et al 2002). A survey of 11 stroke trials identified that early management, on-going rehabilitation and co-ordinated discharge planning were important components of stroke unit care (Langhorne et al 2002).

The researcher argues that stroke unit care offers advantages from a nutritional perspective. Regular multidisciplinary communication is facilitated through weekly multidisciplinary meetings where "*patient problems are identified, rehabilitation goals set, progress monitored and discharge is planned*" (SIGN guidelines 2010 p10). This provides a forum for discussion of overall patient care and allows identification and discussion of any nutritional issues by all members of the team.

This facilitates the provision of a *"a co-ordinated approach to the delivery of food and fluid by different health professionals, and views the patient as an individual with needs and preferences"* which is one of the prerequisites for effective nutritional care defined by Quality Improvement Scotland (NHS QIS 2003 p17). Nutritional care also involves "*the monitoring and reassessment of nutritional status at regular intervals, referral for specialist care when appropriate, and good communication with services in the community"* (NHS QIS 2003 p17). Scottish Intercollegiate Guidelines Network (SIGN 2010) recommends that stroke patients should be screened within 48 hours of hospital admission to assess for malnutrition and the importance of regular nutritional monitoring during rehabilitation phase has been highlighted (Brynningsen et al 2007). Additionally "*good nutritional care will involve training for staff, carers and patients, and access to information*" (NHS QIS 2003 p17). Stroke unit care has incorporated the provision of education programmes and on-going training to equip staff with the knowledge to deliver appropriate care (Langhorne et al 2002).

The researcher postulates that for stroke patients the provision of effective nutritional care lies not necessarily in the nutritional interventions themselves, but in improvements in organisation of care and service delivery that is clearly evident within the stroke unit.

8.3.2 Creation of a post ICU unit

A potential solution to facilitate improvements in nutritional care for post ICU patients would be the creation of a post ICU unit to which all patients would be transferred after discharge from ICU. This option has already been highlighted by Carr (2002) who stated that "*if resources allowed we could transfer all intensive care patients to high-dependency units to continue their recovery, while still providing a better level of support and care than is available on general wards*" (p72). As organisational nutritional care delivery failures have been shown to affect the nutritional intakes of post ICU patients then reorganising care similar to those of stroke units may confer benefits. Identified issues such as lack of knowledge and awareness of nutrition needs after critical illness could be addressed for nursing and

dietetic staff. This would hopefully ameliorate some of the identified problems during transitions of care, service delivery issues and positively influence ward culture. Additionally, social issues with eating could be addressed as provision could be made for a dining room where patients could eat together. This would also lead naturally to patients discussing their critical illness experiences and may help to address some of the psychological problems that have been identified in this study. Mealtimes could also be made more flexible with the provision of additional snacks available at ward level to help address the physiological issues of poor appetite and early satiety which are experienced by this patient group. Simply by being around patients who are experiencing similar physical problems such as fatigue, weakness and varying levels of disability may help others come to terms with their own dysfunctional body and adapt to changes to self and identity. Family members could also be encouraged to be involved in the rehabilitation process by feeding patients, encouraging them at mealtimes, eating with them or bringing in some favourite foods.

Unfortunately the proposed post ICU unit, although potentially offering the most effective way of providing nutritional rehabilitation, would require major reorganisation of NHS services which is unlikely to happen due to cost constraints and logistical implications. In addition some patients will have medical care needs e.g. pancreatitis that require on-going specialist care.

A more practical strategy to promote nutritional recovery in patients after critical illness would be to develop a model of care that addresses the needs of this patient group at ward level. The researcher argues that based on current ward staffing levels it is unlikely that the complex needs of post ICU patients could be fully met.

There is currently no national recommendation for the number of patients per nurse in an acute hospital ward in the UK (RCN 2010). Evidence from other countries, such as Australia, where mandatory nurse-to-patient staffing ratios have been implemented show that nurse staffing levels impact on patient outcomes, patient experience and quality of care (RCN 2012). A UK survey of 9000 nurses in 2009

found that NHS hospital wards have an average nurse-to-patient ratio of 1:8 during the day and 1:11 at night (Ball & Pike 2009). In Victoria, Australia the nurse-to-patient ratio in an acute hospital ward is 1:4 (Gerdz & Nelson 2007). A Workforce Planning Group has been established in the UK to "*try and quantify the volume of nursing work to be provided, and then translate this into the number of people with the right skills*" (RCN 2012 p26). Reflecting this, the finding from this doctoral study have highlighted the complex nutritional needs of post ICU patients and therefore proposes a model of care that utilises a generic rehabilitation assistant to deliver the essential components of a nutritional recovery strategy.

The proposed model of care and the implications for the role of the dietitian addresses two further research questions that emerged from this doctoral study. The research questions were:

- How should current models of dietetic and nutritional intervention be changed to improve nutritional rehabilitation?
- How will the researcher's clinical practice as a dietitian change as a result of the study?

Each of these are discussed in the subsequent two sections.

8.4 Proposed model of care to promote nutritional recovery in patients after critical illness

As highlighted this proposed model of care would utilise a Generic Rehabilitation Assistant (GRA) to deliver the nutritional components of care. This doctoral study, similar to the NICE (2009) guideline, identified the need to address issues during different phases of the patients' hospital journey. The three distinct phases of care are: prior to transfer from ICU, during ward stay and on discharge from hospital. These stages of care are detailed below.

8.4.1 Prior to transfer from ICU

As NHS resources are limited it is important to identify patients who are most likely to have on-going nutritional issues after transfer from ICU. The critical care dietitian

would liaise with a GRA to highlight those most nutritionally at risk. This will include patients who were malnourished prior to admission to ICU, those with existing co-morbidities and patients with a protracted ICU stay.

8.4.1.1 Role of GRA in ICU

8.4.1.1.1 Involvement at mealtimes

It is envisaged that the GRA would be involved in the nutritional care of the patient while they are still in the critical care setting. The researcher, as a clinical dietitian, is aware that meal provision in ICU is often overlooked as decisions are made about oral intake in the morning ward round yet the menu cards are collected early in the morning. This can create difficulties in obtaining meals at lunch time. The GRA could either liaise with the ward hostess to organise meals or obtain food from the canteen. The GRA would be able to provide assistance with feeding at mealtimes and ensure the provision of any additional snacks.

8.4.1.1.2 Early identification of nutrition related issues

The GRA would regularly screen for anticipated problems related to nutrition using tools agreed with occupational therapy, speech and language therapy and dietetic teams. This may include early identification of the need for key assessments such as speech and language therapy for a swallow assessment or occupational therapy for specialist cutlery. Other issues that the GRA could highlight to the multidisciplinary ICU team include identified physiological barriers to eating including nausea, vomiting and diarrhoea.

8.4.1.2 Early involvement of family

Research has demonstrated that family members can provide an important contribution to the care and recovery of the patient in ICU (Williams 2005). In the proposed model of care, based on the findings of this doctoral research, it is envisaged that family members would be encouraged to help feed their relative at mealtimes and bring from home food that the patient previously enjoyed. This contribution to the nutritional care of their relative will help counteract the feelings

of helplessness that have been reported in family members (Holden et al 2002). In order to optimise this contribution to care, family members will need to be provided with relevant information. The GRA would be able to give relevant information such as highlighting the fact that the patient is likely to find eating more difficult, particularly initially. An explanation of the physiological problems which the patient may experience with eating, such as poor appetite, early satiety and taste changes, would help the family understand these difficulties and alleviate some of the tension that was noted in the study with families pressurising patients to eat. Additionally, education could be given about other critical illness related problems affecting eating including psychological issues such as delirium, sleep disturbances and low mood, bodily changes such as weight loss, fatigue, weakness and socio-cultural influences such as social isolation, unfamiliar food and routine. Guidance could also be given about the types of food that could be brought in such as energy dense, protein rich snacks to optimise nutritional intakes. This involvement of the family helps create a culture that "*acknowledges and values the importance of this patient-family-nurse interaction*" (Williams 2005 p13).

8.4.1.3 Co-ordinated multidisciplinary approach to nutritional care

A multidisciplinary team would provide a consistent, systematic approach to the management of the identified physiological factors influencing nutritional intake such as nausea, vomiting and diarrhoea.

The findings from the current study highlighted that ng tubes were often removed on the ward and were not well tolerated by patients for a variety of reasons including physiological, psychological and social issues. If a patient is malnourished on admission to ICU, is likely to have a protracted ICU stay or has a diagnosis that is associated with nutritional issues e.g. pancreatitis, then consideration should be given to the most appropriate route for feeding, taking into account the longer term nutritional issues that these patients are likely to face. A multidisciplinary team discussion could select appropriate patients for jejunostomy or percutaneous endoscopic gastrostomy tubes in order to facilitate effective nutritional care in ICU and after transfer to the ward.

Similarly, a multidisciplinary team approach would be beneficial in the discussion of patients who were ready for discharge to the ward. Patients with on-going or complex issues could be identified and where possible out of hours transfers avoided. The current study demonstrated that patients who were transferred out of hours experienced more nutritional issues on the ward such as removal of ng tubes or failure to deliver nutritional supplements.

8.4.1.4 Systematic handover to ward based staff

A clearly documented nutritional management plan should be handed over to ward staff and appropriate allied health professionals. This nutritional management plan should include any issues influencing nutritional intake in ICU e.g. physiological factors such as poor appetite, early satiety, taste changes, weakness, fatigue or psychological issues such as low mood, delirium. Other information on the management plan should include a description of the patient's current nutritional intake incorporating nutrition from parenteral, enteral and oral routes, food likes and dislikes and details about family involvement in nutritional care. Finally, the plan for on-going nutritional care should be clearly described. Specific recommendations should be clearly communicated to reduce ill-informed decision making by ward based staff such as junior doctors. These recommendations may include the need to continue with enteral feeding or nutritional supplements.

8.4.2 During ward stay

8.4.2.1 The role of the GRA

The current study highlighted the benefits of a GRA in improving patient care for patients after critical illness. It is envisaged that this role would facilitate improvements in nutritional care as highlighted by Agnew (2005) who stated that "*nurses are at the forefront of improving nutritional care but need support from other staff to fulfil their role effectively*" (p27). Nursing staff would continue to have the ultimate responsibility for the patient's nutritional care. However the proposed model of care would utilise the skills of the GRA work with ward based staff to

address the identified nutritional issues from the study. A summary of the traditional approach to nutritional care compared with the proposed model of care for ward based patients is provided in table 32.

Table 32: Comparison of traditional approach to nutritional care with proposed model of care

Traditional approach to nutritional care of post ICU patients	**Proposed approach to nutritional care of post ICU patients**
Fragmented care means ward staff including nurses and doctors are often unaware of problems experienced by patients after critical illness. Patients often isolated in side rooms eating alone in bed. Lack of assistance at meal times to patients who are often weak and fatigued. Restricted family presence during food service time. Systems based approach to delivery of food with set meal times three times a day. Standard portion sizes with a starter, main meal and pudding all served at once. Patients experience physiological and psychological problems after critical illness that are not addressed. Dietetic interventions involving the calculation of nutritional requirements and comparing to actual nutritional intake; documentation of recommendations in medical notes; ordering of nutritional supplements with a reliance of other healthcare professionals to deliver. Poorly co-ordinated discharge and nutritional follow-up.	Use of a generic assistant to promote individualised nutritional care The GRA would liaise with ward staff including nurses, doctors and dietitians. The role of the GRA would include: • providing patient with the opportunity to eat with family members either on ward or in the canteen. • involvement of relatives at meal times on the ward to provide assistance, encouragement and social interaction. • improving problems with poor appetite and early satiety by providing small regular energy dense meals and snacks. • information given to patient about importance of nutrition for recovery and the need to eat foods high in calories and protein to achieve this. • regular feedback to the patient as to whether they are achieving their nutritional goals. • recognising psychological issues associated with critical illness and discussing common problems with patient and if necessary referring to appropriate healthcare professional. • assisting the patient to come to terms with changes to their body, setting patient centred goals for recovery. • early reporting of ongoing nutritional problems to healthcare staff.

	• identification of discrepancies in nutritional decision making for example between medical and dietetic staff • co-ordination of discharge to ensure patient has all relevant nutritional information and follow-up in the community.

It is envisaged that the GRA would work with other healthcare professionals including medical staff, nurses and dietitians to promote individualised nutritional care for patients after critical illness and address the organisational, body and socio-cultural system breakdowns that were identified in this doctoral study.

8.4.2.2 Provision of individualised patient-centred care

The findings from the study highlighted that the provision of nutritional care takes a service centred approach where care is organised around the service and not the patient. The proposed model of care would adopt a more patient-centred approach in the provision of nutritional care. In the UK a patient-centred approach is an integral part of many policy initiatives e.g. The Productive Ward: Releasing Time to Care (NHS Institute for Innovation and Improvement 2007), The 'Better Together' programme (HIS 2011). Manley et al (2011) highlighted that a patient-centred approach should incorporate:

- "*a focus on getting to know the patient as a person, his or her values, beliefs and aspirations, health and social needs and preferences;*
- *enabling the patient to make decisions based on informed choices;*
- *shared decision making between patients and healthcare teams, rather than control being exerted over the patient;*
- *providing information that is tailored to each person to assist him or her in making decisions based on the best evidence available;*
- *supporting the person to assert his or her choices;*
- *on-going evaluation to ascertain that care and services continue to be appropriate for each person*" (p35-36).

In order to facilitate patient-centred processes, consideration needs to be given to the care environment (McCormack & McCance 2006). In the delivery of patient-centred nutritional care the ward routine should be designed to suit the needs of patients. For example, it is recognised that post ICU patients often have problems sleeping therefore provision could be made for a later breakfast to allow these patients to sleep later in the morning. Visiting hours could be adapted to include mealtimes so that family members could provide assistance with feeding and encourage patients to eat. Family involvement in nutritional care would continue from ICU with relatives playing an important role in the social facilitation of eating. Tables and chairs could be provided to allow patients to eat together rather than in or beside their bed. Once a week family members could be encouraged to come in and eat with their relative to further address the social aspects of eating.

The proposed model of care would also involve the GRA having a discussion with the patient regarding their usual eating patterns and food likes and dislikes. Where possible meals could be chosen from the menu however provision should be made for meals from the canteen if suitable food choices or timing of meals could not be accommodated within the hospital meal service. Meals should be served one course at a time to avoid being off-putting for post ICU patients who have small appetites. The GRA should also be able to provide additional snacks on the ward for patients who struggle to eat sufficient quantities at mealtimes due to early satiety. Snack options could include toast, soups, crackers and cheese, biscuits, custard, rice pudding. By encouraging small frequent meals nutritional intakes could be increased without the need for additional nutritional supplements. Another option to avoid the use of nutritional supplements which were not well tolerated by patients in the study would be for the GRA to make milkshakes on the ward according to individual preferences. These could be made with fresh milk, ice-cream and fruit providing a nutritious alternative to prescribable supplement drinks. All of these tasks that have been identified as part of a GRA role could also be carried out by ward volunteers. The volunteers would require a training program to equip them with the necessary information and expertise to carry out these tasks. A study by Walton et al 2008 highlighted the benefits of volunteers at mealtimes; providing assistance with eating

and encouraging patients to eat which led to a concurrent increase in energy and protein intakes.

Patients in the study were often unaware of the importance of nutrition for recovery and the need to eat foods high in calories and protein to achieve this. In the proposed model of care the GRA would have an educational role to provide patients and relatives with information about the nutritional needs after critical illness and provide regular feedback as to whether these nutritional targets were being met. If their nutritional goals were not being met then the GRA could have a discussion with the patient to see if any solutions could be found.

The GRA would also provide the patient with information about the common problems associated with critical illness that influence nutritional intake. This would include physiological changes such as poor appetite, early satiety, taste changes, fatigue, weakness and also psychological issues such as delirium, sleep disturbances and low mood. The GRA would also be able to screen for psychological problems and if necessary discuss any concerns with the appropriate healthcare professional.

Another key aspect of the GRA's role which was found from the study was the relationship that was built between the patient and the GRA. As previously highlighted in Chapter 7, the GRA provides continuity of care for a patient who is often seen by a multitude of other healthcare professionals. This continuity of care builds a level of trust and rapport with the patient and it is through this relationship that the GRA can help the patient come to terms with the changes experienced as a result of critical illness. In an organisation which traditionally *treats* the physical body, the GRA *cares* for the individual as a whole and is ideally placed for assisting the patient to come to terms with changes to their body, self and identity. This is in line with current government priorities to provide 'care' as well as to 'treat' patients. NHS Scotland's action plan states that it should "*deliver patient centred care which is respectful, compassionate and responsive to individual patient preferences, needs and values*" (Scottish Government 2007 p32).

Patients would be seen at least daily by the GRA although it is likely that during the early phase of ward care visits would need to be more frequent, twice or three times a day. Rather than the traditional reactive approach to nutritional care this would allow the instigation of a proactive service as it is known that the majority of post ICU patients will struggle nutritionally especially in the first few weeks. The GRA would provide a clear account of the patients' nutritional care in the medical notes, documenting any on-going nutritional issues or concerns and provide regular feedback to the dietitian.

8.4.2.3 Ward staff education

Although the GRA would be able to address many of the nutritional issues highlighted in the study, it is envisaged that ward staff would also require education about the nutritional needs of the post ICU patient as the GRA would not provide a 24 hour, 7 day a week presence on the ward. A patient care pathway highlighting the specific problems experienced by this patient group would be provided. It would highlight particular nutritional issues that may be experienced by post ICU patients especially during the early phase of their ward stay such as poor appetite, early satiety, taste changes, weakness and fatigue and offer practical suggestions to circumvent these problems. Details would also be provided about the common psychological problems experienced after critical illness and how these may affect nutritional intake. The care pathway would also incorporate information to promote timely referral to appropriate allied health professionals and other services such as psychologists, social workers, alcohol liaison, smoking cessation. Other information would be provided regarding timely drug interventions to address specific problems that influence nutritional intake e.g. diarrhoea, nausea, vomiting, pain, low mood. For example, if antidepressants were being prescribed for depression then prescribing the antidepressant Mirtazapine could also have a beneficial effect of increasing appetite (Chinuck et al 2007).

In addition to a generic patient pathway as described above, an individualised sheet that details patient specific issues would be provided. This patient specific

information would include particular nutritional problems highlighted by the dietitian and GRA that need to be addressed.

8.4.3 Hospital discharge

8.4.3.1 Co-ordinated discharge planning

The findings from the study highlighted issues with poorly co-ordinated discharge planning resulting in patients not receiving adequate dietary advice or information about nutritional supplements prior to discharge. The GRA would be ideally placed to organise any necessary nutritional care for discharge in liaison with the dietitian.

Again as the GRA would not provide a 7 day service, criteria would be detailed in the nutritional care pathway to ensure a safe nutritional discharge. For example the dietitian would need to be informed of imminent discharge so that appropriate information could be given. Nutritional advice on high calorie, protein foods should be given including written information and discussion with family where appropriate. A contact number for the GRA should be given in case the patient has any nutritional queries or concerns after discharge. The GRA would also provide a follow up phone service in the initial period of discharge before patients are reviewed by community dietetic staff.

In view of the fact that community services would not be aware of the patients' journey, their specific issues and on-going needs, it is postulated that for the initial 2-3 months after hospital discharge these patients should be followed up by hospital based teams. Many patients attend specialist out-patient appointments for follow-up and the GRA could organise to review these patients during their clinic visit. This would allow continuity of care and a means of highlighting any on-going ICU related problems to appropriate healthcare professionals.

8.4.4 Care pathway

As part of the proposed model of care, a patient pathway was devised to define the key elements of nutritional care for post ICU patients, based on the findings of the

doctoral study. The European Pathway Association defines a care pathway as "*a complex intervention for the mutual decision making and organisation of care processes for a well-defined group of patients for a well-defined period*" (Vanhaecht et al 2010 p52). Vanhaecht et al (2012) highlighted that care pathways should: describe the purpose and key components of the pathway; promote communication between multidisciplinary team members, patients and families; define the roles and responsibilities of the multidisciplinary team; detail documentation and monitoring and highlight suitable resources. The purpose of a care pathway is "*to enhance the quality of care measured by improving risk-adjusted patient outcomes, promoting patient safety, increasing patient satisfaction, and optimising the use of resources*" (Vanhaecht 2012 p30). The care pathway for the nutritional care of post ICU patients is detailed below.

Care pathway for the nutritional care of patients after critical illness

- The purpose of this care pathway is to provide effective nutritional care for patients after critical illness.

In the Intensive Care Unit	
Goal 1: The patient's nutritional issues are identified early	☐ pre-existing malnutrition prior to ICU admission (BMI<18kgm^2, history of weight loss and/or history of poor nutritional intake) ☐ long ICU stay (>7 days) ☐ swallowing problems Patient experiencing physiological factors influencing nutritional intake. ☐ loss of appetite ☐ early satiety ☐ taste changes ☐ pain ☐ nausea/vomiting ☐ diarrhoea ☐ fatigue ☐ breathlessness ☐ changes to sleep patterns Patient experiencing psychological factors influencing nutritional intake ☐ delirium

	☐ low mood ☐ cognitive changes ☐ depression
Goal 2: The patient's identified nutritional	Handover to ward staff to include: ☐ current route for nutrition
issues are communicated to ward staff	☐ identified factors influencing nutritional intake ☐ nutritional plan
During ward stay	
Goal 3: The patient is receiving the appropriate amount and type of nutrition	☐ weekly completion of MUST screening tool (Appendix 1) ☐ review by dietitian ☐ referral to speech and language therapy (if necessary) ☐ food record charts
Goal 4: The patient's on-going physiological issues are identified	☐ loss of appetite ☐ early satiety ☐ taste changes ☐ pain ☐ nausea/vomiting ☐ diarrhoea ☐ fatigue ☐ breathlessness ☐ changes to sleep patterns Issues are discussed with multidisciplinary team
Goal 5: The patient's on-going psychological issues are identified	☐ delirium ☐ low mood ☐ cognitive changes ☐ depression Issues are discussed with multidisciplinary team
Goal 6: The patient has the appropriate provision of food	☐ meals served one course at a time ☐ meals provided at suitable times ☐ family encouraged to bring in favourite foods ☐ provision of meals from canteen where necessary ☐ additional snacks are provided between meals ☐ assistance with eating is provided where necessary ☐ eating with others is encouraged
Goal 7: The patient is aware of the importance of good nutrition	☐ emphasising the need to eat more for physical recovery ☐ discussion of factors affecting nutritional intake ☐ regular feedback to patient about adequacy of oral intake ☐ involvement of family in discussions
Goal 8: The patient's nutritional needs are discussed regularly by the multidisciplinary team (MDT)	☐ weekly multidisciplinary meetings ☐ dietitian highlights any nutritional issues ☐ the need for nutritional support is reviewed by the MDT
On discharge from hospital	

Goal 9 The patient is provided with appropriate nutritional information	☐ written dietary information ☐ supply of nutritional supplements ☐ contact details ☐ regular follow-up
Goal 10 The patient has the necessary nutritional after care	☐ GRA will contact patient by telephone within the first week of hospital discharge to discuss nutrition ☐ Any problems are fed back to ICU team ☐ GRA will co-ordinate outpatient follow-up with existing specialist clinic appointments within the first three months of hospital discharge

8.5 Next steps in developing and evaluating model of care

This doctoral study has contributed to the development of a theoretical basis for a complex intervention by addressing the development element in the key elements of the development and evaluation process (MRC 2008). The research has provided a theoretical understanding of the process of nutritional recovery after critical illness and the factors which influence this. Guided by the MRC framework for developing complex interventions, the next stage of the research will involve undertaking a feasibility study as part of the modelling process. "*Modelling a complex intervention before a full scale evaluation can provide important information about the design of both the intervention and the evaluation*" (Craig et al 2008 p981).

8.5.1 PICO framework

Other questions which need to be considered at an early stage in developing an intervention include "would it be possible to use this", by whom and in what population or setting (MRC 2008). In order to address these questions and to facilitate the development of the elements of the feasibility study the "PICO" framework can be used. The guidelines highlight the need to define the **P**opulation, **I**ntervention, **C**omparison, and **O**utcome (PICO) (Huang et al 2006). Each of these elements is described in more detail in the sections below.

8.5.1.1 Population

The researcher acknowledges that it is difficult to define the exact population likely to benefit from the intervention and further work may be necessary during the

feasibility stage to define the entry criteria for a trial and this will be an important piece of post-doctoral work. Drawing on the researchers pre doctoral work, the literature review in this thesis and the findings from the doctoral study it is currently envisaged that the inclusion criteria should include patients who had pre-existing malnutrition prior to ICU admission (BMI<18kgm^2, weight loss and/or history of poor nutritional intake). An individualised dietetic assessment would be used to select other patients for inclusion into the study. The dietetic assessment would examine nutritional intake and the need for additional nutritional support, assess nutritional status using weight and weight loss during ICU stay and ascertain the presence of physiological factors influencing nutritional intake such as poor appetite, early satiety, taste changes and weakness. Another factor which may need to be taken into consideration is the presence of ongoing inflammation which may have a detrimental effect on nutritional intake.

8.5.1.2 Intervention

The intervention would be delivered by a Generic Rehabilitation Assistant (GRA) previously modelled in the "Evaluation of a Rehabilitation Complex Intervention for patients following Intensive Care Discharge", The RECOVER study (Appendix 7). The GRA would provide nutritional care to the identified post ICU patients throughout the hospital and provide support after hospital discharge, under the supervision of existing dietitians. The nutritional care would be delivered using the care pathway described above to ensure the provision of effective nutritional care using a patient-centred approach. The intervention components focus on improved coordination and delivery of nutritional care to post ICU patients during their ward stay.

The extended CONSORT guidance for reporting non-pharmacologic randomised trials emphasises the need to fully describe interventions (Boutron et al 2008). In rehabilitation trials the details reported should include the content of therapy sessions, how it was delivered, what information was given to the participants and the instruments used to provide the information. The number, timing and duration of each therapy session should be detailed along with the individual components of

each session. Additionally it was also recommended that reporting included how interventions were tailored to meet individual patient needs (Boutron et al 2008).

The researcher acknowledges these recommendations will be complicated to record in the proposed study as factors such as poor appetite or inflammation could modify the response to treatments. This highlights the need to simply model the intervention using the care pathway to learn how to record the process accurately. Unless the process is captured accurately a future randomised trial may be difficult to interpret because it will not be clear what the difference in actual treatment was between the two groups. Information from the care pathway will be detailed in a taxonomy to facilitate a record and description of what actually happens in the study. The number and timing of sessions by the GRA will be recorded, a description of the content of the session and when the treatments are tailored to individuals. An adequate description of how the care pathway was actually implemented and received by the patients is vital. It is important to ascertain if the intervention is deliverable and acceptable to patients as this will affect the study outcome.

8.5.1.3 Comparison

The comparison would be usual practice and this would involve capturing current nutritional practice on the ward. It is envisaged that a before and after study design would allow details of current nutritional practice to be recorded for a period of three months and then the intervention, delivered by the GRA, to be implemented for another three months. In a before and after study an intervention is introduced, without using randomisation, to observe its effects (Costantini & Higginson 2007). This type of study, often referred to as a quasi-experimental design, is used in health services research as it is more feasible, less expensive and time consuming than randomised controlled trials (Costantini & Higginson 2007). The researcher acknowledges that it is equally important to measure process in the comparison group in order to truly understand the differences between the two groups.

8.5.1.4 Outcome

When evaluating complex interventions there is a need for a range of different outcome measures (MRC 2008) "*A good theoretical understanding of the intervention, derived from careful development work, is key to choosing suitable outcome measures*" (MRC 2008 p12). The researcher argues that her doctoral study has provided her valuable insight into nutritional recovery as the aim was to provide a comprehensive understanding of the factors influencing nutritional recovery, and the relationship between them, in patients after critical illness. The proposed nutritional care pathway is based on the findings from the study and its effectiveness will need to be evaluated with multiple outcomes.

Weight, body mass index, handgrip strength, anthropometry and bioelectrical impedance measurements would be used to detect changes in nutritional status over the three month period. Anthropometric measures such as triceps skinfold thickness and mid arm muscle circumference and bioelectrical impedance measurements will capture changes in body composition. Magnetic resonance imaging may also be carried out to provide detailed images of the body in order to differentiate between fat and muscle mass. The researcher speculates that body mass recovery after critical illness may be from increases in fat mass and not fat free mass. Other nutritional measurements would include a weekly assessment of protein and calorie intake compared to estimated nutritional requirements during hospital stay.

In order to capture patient experience satisfaction measures to assess the acceptability of the intervention or other patient reported outcomes such as visual analogue scales or quality of life measures would be used. Qualitative data from patient interviews would also form an important part in capturing patients' experiences of the components of the nutritional care pathway delivered by the GRA.

This feasibility study would enable the nutritional care pathway, which forms the basis of the intervention, to be modelled in clinical practice. The study would provide an indication of the acceptability and appropriateness of the care pathway in post ICU patients and its potential for improving nutritional recovery. Undertaking the feasibility study would also give an indication of recruitment and retention in the

study and assist in determining the sample size for a larger study. The researcher acknowledges the importance of preliminary work and adequate planning prior to undertaking a larger study in order to address the additional information recommended in the CONSORT guidance for reporting non-pharmacologic trials (Boutron et al 2008). In particular the extended CONSORT guidance emphasises the need to fully describe interventions and process (Boutron et al 2008).

8.6 The role of the dietitian

The researcher recognised from the outset of her doctoral study that it would have implications for her clinical practice and indeed this formed one of the research questions. Reflecting on her research journey, the researcher recognises that her role as a dietitian and the role of dietitians in general in providing effective nutritional care for the post ICU patient has been questioned and scrutinised.

The British Dietetic Association state that "*registered dietitians are the only qualified health professionals that assess, diagnose and treat diet and nutrition problems at an individual and wider public health level. Uniquely, dietitians use the most up to date public health and scientific research on food, health and disease, which they translate into practical guidance to enable people to make appropriate lifestyle and food choices*" (BDA Council 2007). The researcher would argue that there has not been any research to translate into guidance for patients after critical illness. Therefore, dietetic interventions for this patient group have been based on research on disease-related malnutrition. Traditional dietetic interventions involve assessing the patient's nutritional intake and comparing against estimated nutritional requirements. If the patient is not achieving their nutritional target through hospital food then additional snacks or oral nutritional supplements are prescribed. This is a physiological based approach where food is seen as serving a biological purpose.

The researcher questions the efficacy of this approach for post ICU patients based on the findings from this doctoral study and proposes a more individualised patient-centred approach. Dietitians need to be aware of the specific nutritional problems faced by this patient group and recognise the difficulties patients face in achieving

traditional nutritional targets. The role of the dietitian should be to work alongside patients in order to optimise nutrition, taking into account the social, physiological, psychological organisational factors that may influence nutritional intake. This would also involve co-ordinated approach with other healthcare professionals as part of a multidisciplinary team. The dietitian would have a key role in highlighting the issues faced by this patient group and suggesting ways to maximise nutritional intake.

8.7 The limitations of the study

Despite the usefulness of the findings, there are a number of limitations associated with this doctoral study. These limitations relate to a number of methodological issues and the generalisability of the findings.

By studying an area that was remarkably under researched, the researcher had always intended on carrying out an exploratory study to refine her data collection tools. Through undertaking the exploratory study the researcher opted to change her methodology from a case study approach to grounded theory. This was inarguably a good decision as it allowed the research questions to be fully answered, however it did create additional work and the researcher was aware of the time constraints to allow completion of this doctoral work.

The researcher had planned to include patients who were discharged to medical and surgical wards in order to capture organisational factors influencing nutritional care. From the 17 patients recruited into the study, only 5 were on a surgical ward. The patients were recruited from the RECOVER study and it could be argued that patients were, in effect, self-selecting. These patients clearly had an interest in rehabilitation and may have also been aware of their nutritional issues in the ICU.

Although the researcher is satisfied that her chosen data collection methods explored patients' experiences of eating after critical illness, there were inherent limitations associated with the methods. Firstly, the nutritional screening tool identified patients who were well-nourished or malnourished, however it is not designed to capture

changes in body composition. The researcher speculates that patients were losing muscle mass and/or gaining fat mass therefore it would have been beneficial to carry out more specific measures of body composition using anthropometry (measuring fat and muscle mass) or bioelectrical impedance (measuring fat and fat free mass).

The ward based interviews were brief due the high levels of fatigue and impaired concentration experienced by this patient group. At times the researcher would have liked to elicit additional information by probing further into the answers provided. However she was concerned about the interview process becoming onerous for the patient. The researcher acknowledges that her original intent had been to interview staff in addition to patients. As discussed in Chapter 3, the exploratory study found pressures on staff time meant that interviews were not feasible and therefore were omitted from the research design of the main study. Although it would have been beneficial to capture the views of staff the researcher was able to identify some staff related issues through observation of ward practice. Additionally, the fact that staff were too busy to be interviewed was an observation in itself.

Patients were followed up at three months in order to capture the patients' journey during the first three months after ICU discharge. Due to time constraints data were collected during the patients' ward stay and then at three months post ICU discharge. It would have been useful to continue with the weekly interviews and food diaries after hospital discharge to reduce recall bias however it is speculated that this would prove burdensome for this patient group.

Finally, with regard to the generalisability of the research findings, given that the researcher had approached the research inquiry from the qualitative paradigm, the alternative criteria suggested by Schofield (1993) were adopted. Schofield (1993) suggested the concepts 'fittingness', 'comparability' and translatability'. In order to achieve these, a detailed account of the phenomenon, the theoretical position adopted by the researcher and the research methodology is required. This allows the reader to make an informed choice about applicability of the findings to other contexts or patient populations.

In the following section the implications for education, policy and research highlighted by this study are discussed.

8.8 Implications

8.8.1 Implications for education

It is the complexity of the nutritional problems faced by patients after critical illness which are currently not recognised or addressed by ward staff. Nutritional care provision on the ward is for a general hospital patient population and clearly does not meet the needs of post ICU patients. The effects of critical illness impacts on the nutritional intake of patients through a number of interrelated issues with the body, socio-cultural aspects of eating and the organisation of care. Consequently, the nutritional needs of post ICU patients must be addressed in both the graduate and post graduate education of nurses, doctors and dietitians.

8.8.2 Implications for policy

This study has provided insight into the nutritional needs of post ICU patients. The researcher argues that from a healthcare perspective there is a need to integrate these findings into practice. This argument is strengthened by the plethora of reports, guidelines and policies that have been published in an effort to improve the nutritional care for patients in hospital. Despite these, research has continued to demonstrate the on-going prevalence of malnutrition in hospitals (Edington et al 2000, Corish et al 2004, Ruxton et al 2008).

ICU patients utilise enormous hospital resources and there is a recognised need to improve rehabilitation for this patient group (NICE 2009). The systematic review undertaken during NICE guideline development indicated a lack of high quality research concerning interventions to improve rehabilitation of these patients. Rehabilitation, particularly for patients with such diverse problems is a "complex healthcare intervention" for which the Medical Research Council complex framework is appropriate (Campbell et al 2007). These guidelines highlight that too

strong a focus is often made on immediately evaluating an intervention without adequate preliminary development. This results in studies with limited use due to poorly defined rehabilitation interventions that are difficult to implement in clinical practice. In recognition of this, this research study has aimed to explore the complex factors influencing nutritional recovery after critical illness to allow the development of an effective nutritional rehabilitation strategy. It is therefore important for policy makers to be aware of the potential implications of these findings and how they may be implemented to improve nutritional care for post ICU patients.

8.8.3 Implications for research

This research study has developed a theoretical understanding of nutritional recovery after critical care grounded in the experiences of patients. It has highlighted a number of factors that influence nutritional intake in this patient group. Current practice has demonstrated inadequate oral intake and this study has provided an insight into food and eating for post ICU patients. Biomedical research into novel nutritional or pharmacological interventions that may improve nutritional recovery need to take into account the multitude of factors that have been highlighted in this study in order to maximise the likely impact of a novel intervention, such as a modified feed, anti-inflammatory therapy or other pharmacological intervention designed to improve anabolism. This issue would be analogous to testing a drug in a trial without understanding the factors that determine whether patients can or will actually take the drugs as intended.

This doctoral study also includes suggestions for incorporating the findings from the research into practice to improve patients' experiences of eating after critical illness. The findings provide new information and a unique contribution to knowledge of relevance to most NHS hospitals and the multidisciplinary team. The proposed new model of nutritional care will be implemented and evaluated as part of the researcher's recently awarded NRS fellowship. The Medical Research Council recommends cluster randomised controlled trials to study complex interventions like care pathways (MRC 2000). The researcher proposes to use this research design to

evaluate the effectiveness of the nutritional care pathway using patient satisfaction as an outcome measure.

The researcher also found during the course of the research a number of interesting questions emerged which would be valuable to explore further in future research studies. The quantitative results showed that patients had low protein intakes compared to calorie intakes. This led the researcher to consider if patients were putting on weight, whether this was a result of increased fat mass or muscle mass. It would be interesting to examine the impact of increasing physical exercise on muscle mass as the researcher speculates that a combined approach of increasing exercise and ensuring adequate protein intake would promote muscle mass.

8.9 Dissemination

It should be noted that the production and local dissemination of a research report is a condition of the doctoral fellowship provided by the Chief Scientist Office. This research will undoubtedly be of interest to clinical and research staff from the Royal Infirmary of Edinburgh and the wider professional audience such as the Scottish Intensive Care Society and the British Dietetic Association.

It is envisaged that the mixed methods approach will lend itself to publications in critical care journals and also more qualitative social science journals. The researcher is keen to ensure that the research findings are widely disseminated to stimulate discussion and debate on a subject that is remarkably under researched.

8.10 Conclusion

Despite the plethora of nutrition related research *in* ICU, little is known about nutritional recovery in patients after critical illness. The findings from this study provide a unique contribution to knowledge by offering important insights into patients' experiences of eating after critical illness. The substantive theory that emerged from the study revealed that interrelated system breakdowns during the nutritional recovery process influenced patients' experiences of eating after critical

illness. These system breakdowns included experiencing a dysfunctional body, experiencing socio-cultural changes in relation to eating and encountering organisational nutritional care delivery failures.

The study demonstrated that existing processes to provide nutritional rehabilitation to post intensive care patients are not effective and patients fail to meet their nutritional targets. Questions were raised about the acceptability and efficacy of current dietetic interventions for this patient group.

The data from this study suggest that improvements in nutritional care could be achieved by implementing an individualised model of care to address the identified organisational and patient related factors that influence the nutritional recovery of patients after critical illness.

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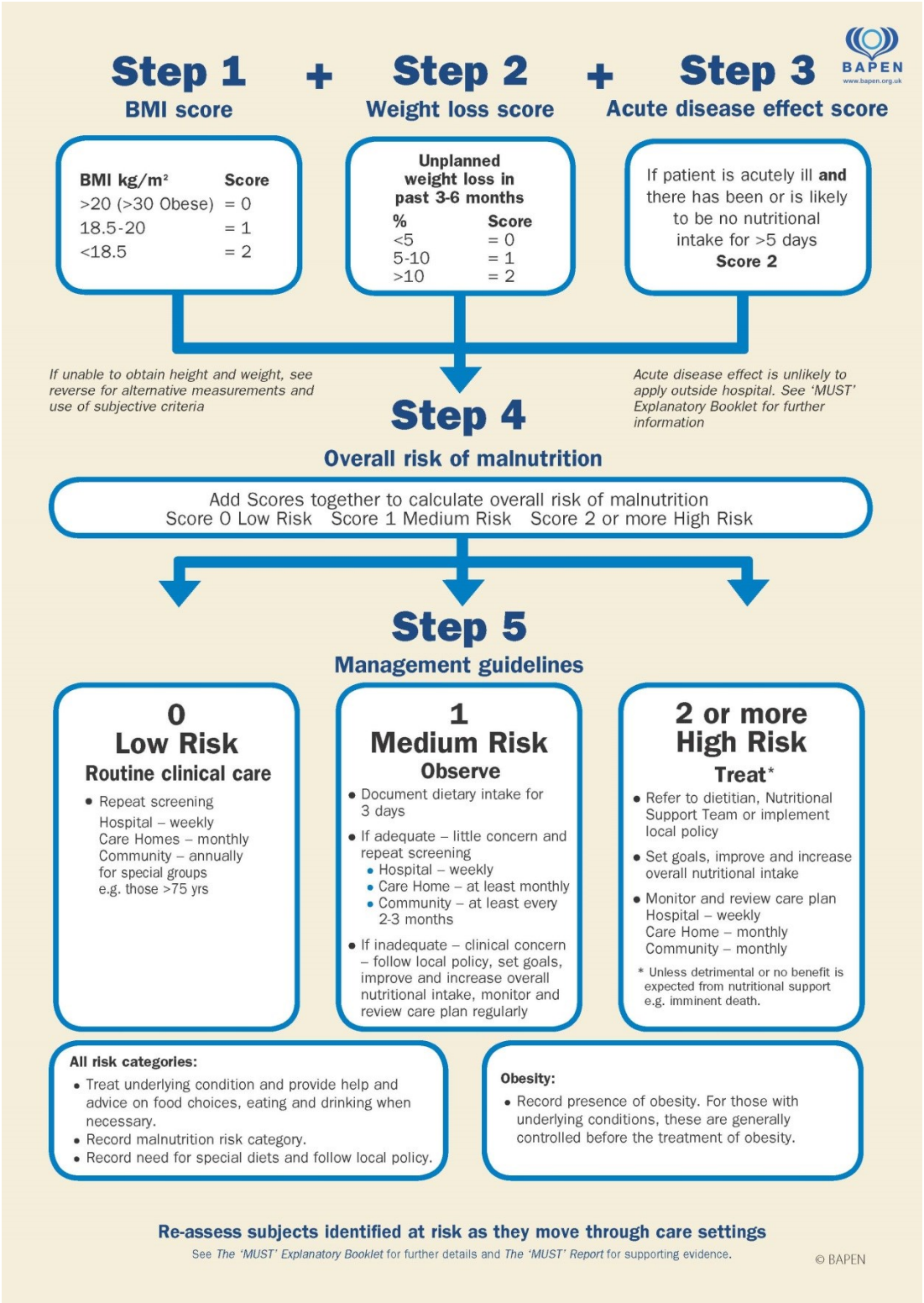
Appendices

Appendix 1 Malnutrition Universal Screening Tool



Appendix 2 Subjective Global Assessment

Instructions

Part A – Medical History

Weight Change:

- "What is your usual weight?" – is post dialysis weight accurate?
- "What is your current weight?"
- "What was your weight 6 months ago?"
    - *Confirm the patient's answer by weighing the patient on a scale and comparing the result to the patient's weight 6 months earlier. .*
    - *Consider signs of fluid overload (oedema/SOB/Hypertension). Accumulation or loss of fluid should not be regarded as real changes in body mass.*
- Calculate the patient's overall weight change over the past 6 months.
- Rate the patient based on the percentage change over the past 6 months.
- Make a separate evaluation based on any change over the past two weeks.
- If the percentage weight loss over the preceding 6 months is less than 5%, this represents an insignificant weight loss therefore score **6 - 7**. (CATEGORY A)
- 5 – 10% weight loss is considered a potentially significant loss therefore score **3 - 5**. (CATEGORY B)
- If the weight loss is >10% = significant loss score **1 - 2**. (CATEGORY C).
- When evaluating obese patients, the same rating guidelines should be followed. Therefore, even if a weight decline is desirable, rate it **1 - 2** (C) if greater than 10% and **3 – 5** (B) if 5 – 10%.

Dietary Intake:

- "Has your dietary intake changed?" – 24 hour recall & compare with requirements.

- Rate whether the patient's status has changed or not, how severe the change is and the duration of the dietary intake change.

    - *Has there been a change in the previous 6 months?*
    - *Has there been a change in the past 2 weeks?*

- The more severe the decline in dietary intake or the longer the duration of the intake decline, the lower the patient should be ranked.

- Is the patient's dietary intake adequate to meet their nutritional requirements?

- Ask the patient if he or she has been placed on a new diet from another healthcare professional. If there is a new diet, it should be evaluated to ensure appropriate nutritional requirements are met**.**

- If a patient is eating well, then no change would be considered therefore score **6 – 7** (A).

- A change would be considered score **3 – 5** (B) or **1 – 2** (C) depending upon the severity of the decline.

- If the patient has not been eating well, then an improvement would be classified as score **6 - 7** (A).

- No change would be rated **3 – 5** (B).

- A further decline would be rated **1 - 2** (C).

- For the 7-point scale, combine dietary intake and GI symptoms for one single score.

Gastrointestinal Symptoms:

- "Have you experienced any persistent GI symptoms?"

- Persistent is defined as those symptoms, which have been present on a daily basis for longer than two weeks.

- Short term (< 2 weeks) or intermittent symptoms are not considered significant.

- The most important symptoms include: nausea, vomiting, diarrhoea, anorexia.

    - *What is the frequency & duration of the symptoms?*

- Rate the patient on the basis of severity of any symptoms mentioned by the patient. The more severe the symptoms, the lower the SGA rating.

Part B – Physical Examination

Loss of subcutaneous fat

Eyes:

- Hollow eyes, loose skin, dark circles: 1-2 (C)
- Slight darkness around eyes, some hollowing: 3-5 (B)
- No hollowing, fat pads: 6-7 (A)

Triceps/Biceps

- Fingers meet when triceps/biceps pinched: 1-2 (C)
- Some fat, not ample: 3-5 (B)
- Ample fat: 6-7 (A)

Muscle wasting

Temples:

- Hollowing, clear depression: 1-2 (C)
- Slight depression: 3-5 (B)
- No depression: 6-7 (A)

Shoulder:

- Line to arm looks square: 1-2 (C)
- Acromion process slightly protruding: 3-5 (B)
- Rounded curve at shoulder and arm: 6-7 (A)

Clavicle:

- Protruding and prominent bone: 1-2 (C)
- Visible in men, protruding in women: 3-5 (B)
- Not visible in men, visible but not prominent in women: 6-7 (A)

Quads:

- Depression/line visible on thigh, thin: 1-2 (C)
- Mild depression on thigh: 3-5 (B)
- Well rounded thigh: 6-7 (A)

Finally

- Use clinical judgement & take a holistic approach.
- Take into account age related tissue loss in elderly patients, they can mimic malnutrition.
- Evaluate tissue loss alongside 'normal' for that patient and against other areas of the SGA.
- Patterns of muscle loss or build can be individual to that patient. Look at the patient as a whole.
- Suggested scoring: take average of 3 scores.

Subjective Global Assessment Scoring Sheet

Part A: Medical History

1. Weight change

Usual dry weight: _____ kg
Current dry weight: _____ kg
Weight 6 months ago: _____ kg
Overall change in past 6 months: _____ kg _____%

Percentage change over past 6 months:
□ gain or <5% loss
□ 5-10% loss
□ >10% loss

Change in past 2 weeks:
□ increase
□ no change

SGA Score 1: Weight change						
Severe		**Moderate**		**Mild**		**Normal**
1	**2**	**3**	**4**	**5**	**6**	**7**

2.1 Dietary intake

□ no change: □ adequate intake
□ inadequate intake

□ change: □ increase
□ decrease

Overall duration: _____weeks

Change in previous 6 months:
□ yes
□ no

Change in past 2 weeks:
□ yes
□ no

SGA Score 2: Dietary intake & GI symptoms						
Severe		**Moderate**		**Mild**		**Normal**
1	**2**	**3**	**4**	**5**	**6**	**7**

2.2 Gastrointestinal Symptoms

□ anorexia; □ nausea; □ vomiting; □ diarrhoea Duration: _____weeks.

Part B: Physical Examination

Evidence of:
Loss of subcutaneous fat
Muscle wasting

SGA Score 3 & 4: Physical Examination						
Severe		**Moderate**		**Mild**		**Normal**
1	**2**	**3**	**4**	**5**	**6**	**7**

Part C: SGA Classification

SGA Classification						
Severe		**Moderate**		**Mild**		**Normal**
1	**2**	**3**	**4**	**5**	**6**	**7**
C		**B**			**A**	

Appendix 3 Examples of revised interview questions

Stage in the critical illness journey	Questions	"Prompts & Probes"
Transfer from ICU	What was your eating like before you were in intensive care? Can you tell me how you ended up in ICU? What's eating like for you at the minute? How have you been feeling about what has happened to you?	Did you have a good appetite, eat three meals? Were you unwell for a while? Are you eating like you normally would? Eg upset, unaware, concerned
Ward	Can you tell me how your eating been this week? Is there anything that has made eating more difficult for you this week? What has the main issue been for you this week? Is there anything else you think might be relevant?	How is it different from normal? Eg lack of appetite, problems with meals What has concerned you the most eg fatigue, mood etc
Three months post ICU discharge	How did you get on when you first got home? Has your eating changed since you were in hospital? Is there anything that has made eating easier or harder since you have been at home?	A lot of people find the first few weeks at home quite difficult. Do you feel like you are eating more? Eg home cooked meals, social eating

Appendix 4 Case report form

Exploration of the barriers to nutritional intake after intensive care.

Subject Number ☐☐

Week ☐

Date of collection ☐☐/☐☐/☐☐☐☐

A pilot study to explore the barriers to nutritional intake after intensive care.

Visual Analogue Scores

	Value measured from VAS	Patient unable to complete	Patient refused to complete
Breathlessness			
Appetite			
Pain			
Fatigue			

Nutritional Intake

Estimated calorie requirements □□□□

Estimated protein requirements □□□□

Actual calorie intake (from one food chart) □□□□

Actual calorie intake (from average of food chart) □□□□
Number of food charts used to gain average _____

Calorie intake as a % of requirements _____

Actual protein intake (from one food chart) □□□□

Actual protein intake (from average of food chart) □□□□
Number of food charts used to gain average _____

Protein intake as a % of requirements _____

Visual Analogue Scales

0	10
No breathlessness	Worst breathlessness imaginable

0	10
No appetite	Best appetite imaginable

0	10
No pain	Worst pain imaginable

0	10
No fatigue	Worst fatigue imaginable

Observation prompts	
1. Space: the physical place or places 2. Actor: the people involved 3. Activity: a set of related acts people do 4. Object: the physical things that are present 5. Act: single actions that people do 6. Event: a set of related activities that people carry out 7. Time: the sequencing that takes place over time 8. Goal: the things people are trying to accomplish 9. Feeling: the emotions felt and expressed	**Meal times** - time of meal - who served - position of patient - how was it served - assistance given - who took it away - was intake recorded - patient/staff interaction

Field notes	
Observations	Insights and reflections

Appendix 5 Food diary

Please record all food and drink intake for a day. Please be specific as possible and include details such as type of milk, butter or margarine, brown or white bread, milk and/or sugar in tea/coffee.

Date **Day**	**Record type and amount of food eaten**
Breakfast	
Midmorning	
Lunch	
Midafternoon	
Dinner	
Bedtime	

Appendix 6 CAM ICU

CAM-ICU Worksheet

Feature 1: Acute Onset or Fluctuating Course	Score	Check here if Present
Is the pt different than his/her baseline mental status? OR Has the patient had any fluctuation in mental status in the past 24 hours as evidenced by fluctuation on a sedation scale (i.e., RASS), GCS, or previous delirium assessment?	Either question Yes →	☐
Feature 2: Inattention		
Letters Attention Test (See training manual for alternate **Pictures**) Directions: Say to the patient, *"I am going to read you a series of 10 letters. Whenever you hear the letter 'A,' indicate by squeezing my hand."* Read letters from the following letter list in a normal tone 3 seconds apart. **S A V E A H A A R T** **Errors are counted when patient fails to squeeze on the letter "A" and when the patient squeezes on any letter other than "A."**	Number of Errors >2 →	☐
Feature 3: Altered Level of Consciousness		
Present if the Actual RASS score is anything other than alert and calm (zero)	RASS anything other than zero →	☐
Feature 4:Disorganized Thinking		
Yes/No Questions (See training manual for alternate set of questions) 1. Will a stone float on water? 2. Are there fish in the sea? 3. Does one pound weigh more than two pounds? 4. Can you use a hammer to pound a nail? **Errors are counted when the patient incorrectly answers a question.** **Command** Say to patient: "Hold up this many fingers" (Hold 2 fingers in front of patient) "Now do the same thing with the other hand" (Do not repeat number of fingers) *If pt is unable to move both arms, for 2nd part of command ask patient to "Add one more finger" **An error is counted if patient is unable to complete the entire command.**	Combined number of errors >1→	☐

Overall CAM-ICU		
Feature 1 plus 2 and either 3 or 4 present = CAM-ICU positive	**Criteria Met →**	☐ **CAM-ICU Positive** (Delirium Present)
	Criteria Not Met →	☐ **CAM-ICU Negative** (No Delirium)

Appendix 7 RECOVER protocol

Open Access Protocol

BMJ open accessible medical research

A randomised controlled trial evaluating a rehabilitation complex intervention for patients following intensive care discharge: the RECOVER study

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ABSTRACT

Introduction: Patients who survive an intensive care unit admission frequently suffer physical and psychological morbidity for many months after discharge. Current rehabilitation pathways are often fragmented and little is known about the optimum method of promoting recovery. Many patients suffer reduced quality of life.

Methods and analysis: The authors plan a multicentre randomised parallel group complex intervention trial with concealment of group allocation from outcome assessors. Patients who required more than 48 h of mechanical ventilation and are deemed fit for intensive care unit discharge will be eligible. Patients with primary neurological diagnoses will be excluded. Participants will be randomised into one of the two groups: the intervention group will receive standard ward-based care delivered by the NHS service with additional treatment by a specifically trained generic rehabilitation assistant during ward stay and via telephone contact after hospital discharge and the control group will receive standard ward-based care delivered by the current NHS service. The intervention group will also receive additional information about their critical illness and access to a critical care physician. The total duration of the intervention will be from randomisation to 3 months postrandomisation. The total duration of follow-up will be 12 months from randomisation for both groups. The primary outcome will be the Rivermead Mobility Index at 3 months. Secondary outcomes will include measures of physical and psychological morbidity and function, quality of life and survival over a 12-month period. A health economic evaluation will also be undertaken. Groups will be compared in relation to primary and secondary outcomes; quantitative analyses will be supplemented by focus groups with patients, carers and healthcare workers.

Ethics and dissemination: Consent will be obtained from patients and relatives according to patient capacity. Data will be analysed according to a predefined analysis plan.

ARTICLE SUMMARY

Article focus

- The optimum method to maximise the rate and magnitude of recovery following an illness requiring intensive care is unknown.
- Rehabilitation is a complex healthcare intervention, which following critical illness involves multiple healthcare professionals including doctors, nurses, physical therapists, dietitians, occupational therapists and other allied professionals.
- The RECOVER trial hypothesises that providing more coordinated and intensive rehabilitation, delivered by a specialised generic rehabilitation assistant supported by the existing multidisciplinary team, will improve recovery as judged by a range of patient-centred outcome measures and is cost-effective.

Key messages

- The RECOVER study will evaluate whether enhanced rehabilitation is clinically effective and cost-effective in patients enrolled at the time of ICU discharge.
- Both positive and negative results will be clinically important in guiding future research directions and health service improvement.

Strengths and limitations of this study

- RECOVER was informed by the recommendations of recent evidence-based NICE guidance, and a significant body of research was used to develop the intervention.
- The trial has been designed to adhere closely to recent guidance concerning the evaluation of complex healthcare interventions, especially the measurement of process.
- A weakness may be the inclusion of patients with a range of illness severity and disability from a general intensive care population; this could miss important effects in patient subgroups.

Trial registration: The trial is registered as ISRCTN09412438 and funded by the Chief Scientist Office, Scotland.

INTRODUCTION AND BACKGROUND

Survivors of critical illness frequently suffer from severe disabilities that include physical, psychological, and social problems. These typically persist for many months, may not resolve completely[1–3] and are associated with reduced health-related quality of life (HRQoL), which often fails to achieve preillness levels.[1–4] The direct (healthcare) and indirect (carers/family) costs during this period are probably high but are not well studied. In the UK, a recent report ('Quality Critical Care')[5] and a NICE guideline[6] have highlighted the need to improve rehabilitation for this patient group. A systematic review undertaken during NICE guideline development indicated a lack of high-quality research concerning what interventions improve patient outcomes and their clinical and cost-effectiveness.[6] Recommended future research questions included: "For patients at high risk of critical illness-associated morbidity, what is the clinical effectiveness and cost effectiveness of organised critical care rehabilitation versus usual care on physical and psychological functioning, participation and quality of life?"

Our pretrial work identified the following key issues in this area:

Patients have wide ranging health problems: the health problems that follow critical illness have been called the 'post-ICU syndrome'.[2] *Physical impairment* is typified by malnutrition, which is worsened by poor appetite and nausea. Patients can lose 10%–30% of their body mass during critical illness.[3] Recovery is further delayed by joint stiffness, pain and neuropathies; levels of fatigue and breathlessness are high. Muscle weakness is particularly common and strongly associated with poor outcome. Problems with *psychological health and social functioning* are also common.[7 8] Anxiety, depression and post-traumatic psychopathology (such as post-traumatic stress disorder) are reported in 10%–40% of patients. These problems are rarely screened for or addressed in most acute hospitals.

Patient rehabilitation is currently not coordinated: survivors are currently managed in acute hospitals with inconsistent fragmented strategies post-intensive care unit (ICU) discharge. Typically, specialty-based teams lead care and patients are widely dispersed within the hospital. Importantly, patients effectively 'compete' with less sick patient groups (eg, elective surgery patients) for limited rehabilitation resource. In a local audit, we found that 70% of patients were discharged directly home from the acute hospital without clearly planned rehabilitation.[9] Coordination with primary care services was poor and inconsistent, and knowledge of the specific problems faced by the post-ICU patient was very limited among staff on the general wards and after discharge to the community.

Patients are major users of acute hospital resource: intensive care costs are high, mainly because of the high staffing levels required to provide multiple organ support on an individual patient basis. The duration of ICU stay is skewed towards a median stay of 2–3 days in most healthcare systems, but the minority of patients requiring longer ICU stay utilise the majority of ICU bed days and continue to utilise enormous hospital resource post-ICU discharge as a result of their residual disability. As the population ages and numbers of ICU admissions are expected to increase, this cohort of ICU survivors will place increasing pressure on acute hospital services. Clinically effective rehabilitation strategies therefore have potential to be both efficient and cost-effective.

Patient outcomes are poor: many patients report poor pre-ICU HRQoL and have chronic health problems prior to ICU admission,[1] but HRQoL is significantly reduced in most patients following ICU discharge. Impaired physical function is particularly common during the first 3–6 months after discharge.[1 4] Typically, recovery of HRQoL takes at least 12 months. Over 50% of patients are below retirement age and only half of those previously working have returned to work by 12 months. Patients have an excess risk of death compared with age- and sex-matched population for up to 5 years after discharge.[10]

Little research has evaluated interventions to improve outcomes following ICU discharge. A small randomised controlled trial (RCT) showed that self-help manuals, supported by a researcher, improved physical function at 6 months.[11] A recent randomised trial found improvements in physical function at hospital discharge associated with early mobilisation in the ICU but did not address longer term patient benefits or report cost-effectiveness.[12] Many critical care services provide nurse-led follow-up clinics at 3–12 months after hospital discharge, but this approach has little, if any, emphasis on the early recovery phase and a recent randomised trial was unable to demonstrate any clinical benefits or cost-effectiveness.[13]

Our pretrial work included a qualitative interview-based study evaluating the experience of 20 survivors of long-term ventilation during the 6 months following ICU discharge.[14] We found that patients experienced profound debilitation during the ward phase of recovery and were frustrated by fragmented or specialty-led care, which seemed neither to take account of their individual needs nor issues specific to critical illness. Many were distressed by a perceived indifference among busy ward staff towards their significant dependence and needs. Concerns focused on the brevity and perceived inadequacy of rehabilitative provision (especially physiotherapy), while others felt 'outside' the rehabilitation process, in terms of their individual contribution and longer term goals and strategies. Many patients were discharged home with limited understanding of the nature or severity of their critical illness, which contributed to unrealistic expectations of recovery. In general,

patients were ill equipped to manage their own recovery following hospital discharge and had limited access to clinicians in order to address their concerns. We developed a service model based around a generic rehabilitation assistant (GRA) to coordinate and deliver rehabilitation for these patients throughout their hospital stay and maintain contact after hospital discharge.[15] In our model, rehabilitation is planned and supervised by 'hard-stretched' specialist staff (physiotherapists, dietitians, occupational therapists) but delivered by a single specifically trained GRA who develops a close relationship with the patient. We tested our model in a feasibility RCT and showed that markedly enhanced levels of treatments could be successfully delivered with this model, and the GRAs could function autonomously across specialist boundaries in the acute hospital.[9] We further refined our service model to include a GRA training programme, predefined competencies and input from critical care staff to provide information to patients and families.

METHODS

Trial objectives

Our primary objective is to evaluate the impact on physical, psychological and social functioning of a novel complex intervention strategy to enhance delivery of physical and nutritional rehabilitation to patients during the 3 months following ICU discharge. Our secondary objectives are to evaluate the cost-effectiveness of our approach and compare patient and carer experiences and satisfaction between usual care and the new strategy.

General design

RECOVER is a prospective, randomised, parallel group, controlled trial with concealment of outcome assessment. We are comparing our novel intervention with usual care. A schematic diagram describing the trial structure is shown in figure 1. The primary study outcome is the Rivermead Mobility Index (RMI) at 3 months postrandomisation, which is a measure of physical function in relation to mobility. As this is a trial of a complex intervention with potential effects on many outcomes important to patients and health services, we are measuring a range of secondary outcomes during 12 months of follow-up (table 1). The full trial protocol is available on the Edinburgh Clinical Trials Unit (ECTU) website: http://www.clinicaltrials.ed.ac.uk.

Trial setting

The trial is taking place in Lothian Health Board's two major acute hospitals, which serve Edinburgh and the surrounding region. The hospitals are run as a single organisation with each major specialty grouping managed by a clinical director and management team. The critical care service is run as a discrete directorate with a single general critical care unit on each site. The Edinburgh Royal Infirmary ICU cares for approximately 700 mechanically ventilated patients each year and the Western General hospital ICU approximately 450 patients. Cardiac surgery and paediatric critical care are provided in separate ICUs. Further information about the critical care setting is available in the Scottish Intensive Care Society Audit report (http://www.sicsag.scot.nhs.uk/).

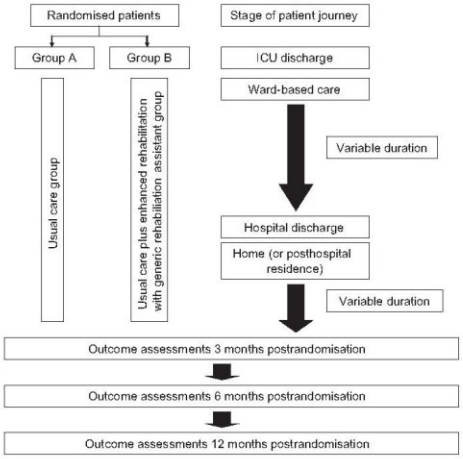

Figure 1 The general structure of the RECOVER trial.

Subject screening and selection

All ICU admissions will be accounted for, and those receiving 48 h of continuous ventilation will be screened for eligibility. *Inclusion criteria* are the patient required ≥48 h of continuous invasive (via an endotracheal and/or tracheostomy tube) mechanical ventilation in the ICU and the consultant in charge of the patient considers them fit for discharge from the ICU. *Exclusion criteria* are a primary neurological admission diagnosis (brain trauma, intracerebral bleed, stroke, Guillain–Barre syndrome); the clinician in charge of care has agreed with the patient and/or family that only palliative care will be provided; patients currently receiving home ventilation or planning to commence a programme of home ventilation; patients expected to be discharged from ICU to a non-study hospital where the intervention cannot be received; gaining informed consent following the intervention or follow-up is not feasible due to communication difficulties; the patient currently enrolled in another RCT with similar endpoints and aged <18 years at the time of screening. The recruitment window will be up to 7 days from the time the patient fulfils entry criteria.

Consent

The study involves participants who may lack capacity as a result of acute illness. For these patients, the Adults with Incapacity Act (Scotland; 2000) applies. Patients

Table 1 The patient outcomes measured in the trial

	Method of assessment	Outcome	Measurement tool (where appropriate)
Primary outcome	Research coordinator blinded to group allocation	Physical function	Rivermead Mobility Index 3 months postrandomisation
Secondary outcomes			
Hospital	Research coordinators	Length of stay ICU readmission rate Survival to hospital discharge Weekly physical function Weekly levels of fatigue, breathlessness, appetite, pain and joint stiffness Weekly presence of delirium Weekly hand grip strength	Rivermead Mobility Index Visual analogue scores Confusion-Agitation Method for ICU Hand grip dynamometry
3 months	Research coordinator blinded to group allocation	HRQoL Levels of fatigue, breathlessness, appetite, pain and joint stiffness, patient satisfaction*, healthcare resource use, anxiety and depression Nutritional status (subjective global assessment of nutrition), weight/BMI, hand grip strength, physical mobility, post-traumatic stress disorder symptomatology	Total, Physical Component Score and Mental Component Score SF-12 score, Visual analogue score Patient satisfaction measure, Health Economic Questionnaire, Hospital Anxiety and Depression (HAD) Questionnaire Physical component of the Subjective Global Assessment of Nutrition tool Hand grip dynamometry, 2 m timed up-and-go time, Davidson's Trauma Scale Score (DTS)
6 months	Postal questionnaires	Survival, physical function HRQoL Levels of fatigue, breathlessness; appetite; pain and joint stiffness, Healthcare resource use, Anxiety and depression Post-traumatic stress disorder symptomatology	Rivermead Mobility Index, Total, Physical Component Score, and Mental Component Score SF-12 score, Visual analogue score Health economic questionnaire, Hospital Anxiety and Depression (HAD) Questionnaire Davidson's Trauma Scale Score (DTS)
12 months	Postal questionnaires	Survival, Physical function HRQoL Levels of fatigue, breathlessness, appetite, pain and joint stiffness Healthcare resource use, anxiety and depression Post-traumatic stress disorder symptomatology	Rivermead Mobility Index, Total, Physical Component Score, and Mental Component Score SF-12 score, Visual analogue score Health Economic Questionnaire, HAD Questionnaire Davidson's Trauma Scale Score (DTS)

*The patient satisfaction measure used in the trial was derived based on data obtained in the pretrial work, especially the qualitative research in reference[14]. The tool is available on the RECOVER page of the ECTU website (http://www.clinicaltrials.ed.ac.uk).
HRQoL, health-related quality of life; ICU, intensive care unit.

with mental capacity will be approached for consent to participate in the trial. For those lacking mental capacity, the welfare attorney or next of kin will be approached for consent. For patients enrolled with this approach, patients will be approached for consent to remain in the trial once they regain capacity. The study information sheets are available on the ECTU website (http://www.clinicaltrials.ed.ac.uk).

Sample size

Based on our pilot study, we estimated that the mean (SD) RMI at 3 months postrandomisation will be 10 (4.3), with normal mobility being 15 on a 0–15 scale. Our pilot data suggested a change from baseline to 3 months in RMI of 2 (SD 5) is currently typical.[9] We have powered the study to detect an improvement in the change from baseline RMI of 2 points at 3 months in the intervention group compared with usual care. This would be a clinically relevant difference in physical disability for patients in relation to activities of daily living and independence. To detect this difference, we require 100 evaluable patients per group at 3 months (80% power; 5% significance level). Assuming a 12% death rate before 3 months (based on pilot work) and

95% follow-up of remaining patients at 3 months (facilitated by home visits by research nurses), we require to randomise 240 patients in total. Using local audit data, we estimated that 498 eligible patients will be cared for each year of whom 309 will be discharged alive from ICU. Assuming 70% enrolment, we expect to enrol 216/year or 18/month. The planned recruitment period is therefore 14 months.

Method of assignment to treatment groups

Patients will be randomised 1:1 to receive either existing usual care or the novel intervention. Randomisation will be by a remote computer-based telephone system to ensure allocation concealment. At randomisation, minimisation with a random element will be used to balance the following baseline variables: age (>65 vs ≤65 years); disability at study entry (RMI 0–5 vs 6–10 vs 11–15); nutritional status at randomisation (physical assessment element of the Subjective Global Assessment of nutrition[16]: malnourished versus well nourished); the presence/absence of delirium (using CAM-ICU) and the ward destination of patient (surgical vs medical).

Study intervention

Duration

The study intervention will start from the time of patient randomisation, which will be within 48 h of consent, and last until 3 months postrandomisation. Patients are expected to require variable periods of time in the acute hospital and the community during the 3-month intervention, depending on individual health status. Following the 3-month assessment, all patients will receive usual care irrespective of their location, but relevant healthcare professionals will be made aware of any key issues by the research team to ensure patient safety. Based on audit data, we expect only a small proportion of patients to remain in hospital at 3 months when the primary outcome is measured.

Description of treatments received

RECOVER is a complex intervention trial and, as recommended by the MRC complex intervention framework, we are describing the process of care received in each group in detail.[17] To achieve this, we have identified four key stages of the patient pathway during which we believe key and important components of rehabilitation occur. These comprise the immediate post-ICU discharge period (stage 1); ward-based rehabilitation in the acute hospital (stage 2); acute hospital discharge planning (stage 3) and the posthospital discharge period (stage 4). These stages will have differing durations and timings in relation to randomisation according to individual patient requirements. The processes and treatments that we want to measure during each stage have been defined a priori and will be recorded prospectively according to a proforma (see data collection and table 2).

Intervention group procedures

Generic rehabilitation assistants

GRAs will be employed to work exclusively with patients randomised to the intervention group. We previously described the concept of the specialist critical care rehabilitation assistant.[15] For RECOVER, we calculated that the workload would require 2.5 whole time

Table 2 The process measures and treatments recorded prospectively to describe the rehabilitation received during the intervention period

Stage	Process	Data recorded by
One: post-ICU discharge	Visits by ICU clinical staff Provision of rehabilitation manual by research team	Research nurse from medical notes
Two: ward-based rehabilitation Documented for each week (or part week) in the acute hospital	Number of visits (and content) by physiotherapy staff, occupational therapy, SLT, dietetic and other non-parent specialty staff Number of visits by GRA (intervention group only) Total numbers of therapy sessions in physiotherapy, dietetic, occupational health, SLT and other relevant categories Patient-centred goals documented	Research nurse from medical notes
Three: hospital discharge	Number patient discharged to rehabilitation facility For patients discharged to home/community: Proportion of patients receiving home visit occurred Proportion of patients with letter to general practitioner specifically documenting rehabilitation issues	Research nurse from medical notes
Four: post-hospital discharge to 3-month outcome measure	Total contacts with GRA during post-hospital discharge period Contact with healthcare services	Research nurse at 3 months assessment

GRA, generic rehabilitation assistant; ICU, intensive care unit.

equivalent posts working flexibly across the two hospitals under the supervision of a multidisciplinary rehabilitation team comprising physiotherapists and dietitians and some input from speech and language therapy and occupational therapy. The GRAs will be trained to use systematic screening tools for common problems and deliver therapy according to predefined competencies. All GRAs will receive a 4-week training programme prior to starting the trial. A description of the training programme is available on the RECOVER page of the ECTU website (http://www.clinicaltrials.ed.ac.uk).

Stage 1 interventions

A lay summary will be produced by an ICU consultant or nominated member of staff and made available to patients, their relatives and relevant healthcare professionals providing a brief summary of key events that occurred during the patient's stay in intensive care. All patients will receive a visit from a Critical Care consultant or nominated deputy, organised by the GRA for an appropriate time mutually convenient to the patient, the consultant and the patient's relative (if they wish to attend). A predefined topic guide will be used to cover key aspects of the critical illness pathway and will include possible short- and long-term complications. The proforma used to dictate the lay summary, and the topic guides used for the consultant visit are available on the RECOVER page of the ECTU website (http://www.clinicaltrials.ed.ac.uk).

Stage 2 interventions

The GRA will deliver an enhanced and coordinated rehabilitation under the supervision of the multidisciplinary specialists, based on frequent visits according to the requirements of individual patients and clinical workload. Key elements will include the following: individualised goal setting with each patient in a range of areas; a clear plan of exercises and nutrition interventions aimed at achieving the goals; regular systematic screening for anticipated problems relating to nutrition and physical disability using tools agreed with physiotherapy, dietetic, occupational therapy and speech and language therapy teams. These will be used to trigger specialist input using predefined thresholds or criteria. The screening tools used by the GRAs to detect patient problems and refer to more senior specialists within the rehabilitation team are available on the RECOVER page of the ECTU website (http://www.clinicaltrials.ed.ac.uk).

Stage 3 interventions

The GRA will input into hospital discharge planning by the multidisciplinary team based on their detailed knowledge of ongoing patient problems and issues.

Stage 4 interventions

After discharge home, the GRA will contact the patient within the first week to enquire how they are managing at home and whether there are any issues that have arisen. The patient will be provided with a telephone number at discharge, through which they can contact the GRA to discuss any issues.

Usual care procedures

The NICE guideline makes recommendations regarding best practice but acknowledges that these are largely expert/opinion based or based on extrapolation from other rehabilitation settings.[6] Our pretrial work showed that the intensity of physiotherapy and dietetic input was limited and that ward visits by ICU clinicians is not routine care. The strongest evidence for effectiveness on physical recovery was provision of a self-help manual, supported by expert staff, during the weeks after ICU discharge.[11] For the purpose of RECOVER, we intend 'usual care' to be externally valid as representative of practice in the NHS (or other healthcare systems). We will include provision of an ICU recovery manual as part of 'usual care' because data exist to support this intervention. Otherwise rehabilitation will be provided by NHS multidisciplinary teams using the current arrangements in the study hospitals, which does not include any specialist critical care GRAs. Detailed process data collection for both groups will ensure that the treatment received in both arms is well described.

A summary of the interventions expected to occur at each stage of recovery for each group is summarised in figure 2.

Data collection

Baseline data

We will record age, gender, social class (postcode based), Functional Co-morbidity Index (based on prehospital admission data), ICU diagnosis (Scottish Intensive Care Society code) and APACHE II score at ICU admission. At randomisation, we will record prerandomisation ICU length of stay and total hospital length of stay; days of mechanical ventilation, vasopressor use and renal replacement therapy; source of nutrition at study entry; Sequential Organ Failure Assessment score at randomisation; delirium at randomisation (CAM-ICU tool); RMI and the physical component of the Subjective Global Assessment of Nutrition tool score.

Process of care data

Detailed quantification of predefined elements of rehabilitation will be recorded on a weekly basis by research staff from randomisation until hospital discharge. These fields are summarised in table 2.

Outcome data

The primary and secondary outcome data are summarised in table 1. At 3 months postrandomisation, all surviving participants will be contacted and a home visit undertaken by community research nurses blinded to group allocation, with no previous knowledge of the participant. Patients remaining in hospital at 3 months will be assessed by research staff blinded to group allocation. At 6 and 12 months, postrandomisation surviving patients will be contacted by the trial office and

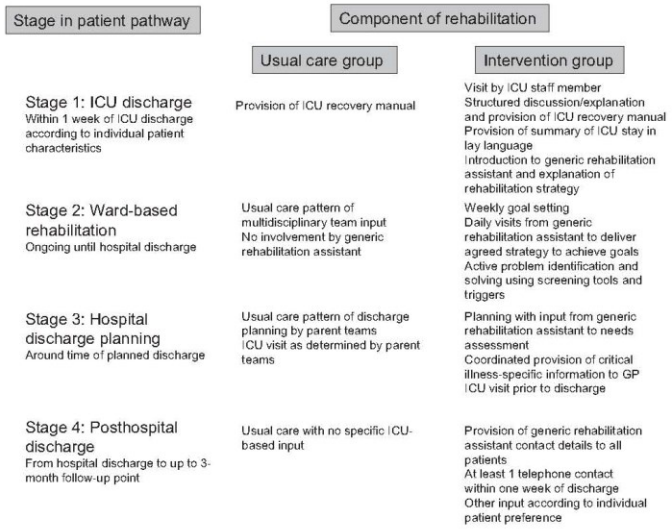

Figure 2 A description of the conceptual stages in the patient journey and the intended differences in the rehabilitation provided for the two groups.

outcomes measured using postal questionnaires. A predefined standard operating procedure will be used to maximise rates of follow-up and completion of the primary and secondary outcomes; this is summarised on the RECOVER page of the ECTU website (http://www.clinicaltrials.ed.ac.uk). Patient survival up to 10 years will be ascertained through linkage to the Information and Services Division Database through the Scottish Intensive Care Society Audit Database. The proposed CONSORT diagram is shown in figure 3.

Data management

All data will be collected to paper Case Record Files and entered into a bespoke database. Quality checks will generate queries, which will be resolved with research site staff. All data queries will be resolved prior to locking the database for analysis. Data will be stored in the ECTU or associated data archiving facilities for a minimum of 15 years to enable subsequent ascertainment of long-term health status through national database linkage.

Data analysis

The primary analysis will be performed according to the intention-to-treat principle. As the trial is testing a complex intervention involving health service redesign, we do not propose a separate analysis of patients who did not receive any or certain elements of the intervention. The primary outcome measure, RMI at 3 months postrandomisation, will be compared between the groups using analysis of covariance to adjust for baseline RMI and for the factors included in the minimisation algorithm. A sensitivity analysis will be performed where the lowest possible value of RMI (0) is imputed for those patients who die within 3 months of randomisation. A similar approach will be used to analyse the secondary outcome measures. A detailed analysis plan has been written for the baseline variables, process measures and primary and secondary outcome variables. The analysis plan is available on the ECTU website (http://www.clinicaltrials.ed.ac.uk).

Qualitative study

We plan to maximise the information obtained about the intervention using a mixed methods approach, incorporating qualitative research. Focus group interviews will be conducted, recorded and transcribed at each of the participating hospitals.

Patients and carers

Using purposive sampling, we will invite 8–10 patients and carers from the 'usual care' and intervention groups at each site to participate in separate focus groups. Participants will be invited to discuss their experiences of recovery and rehabilitation up to 3 months post-ICU discharge. We will explore key issues and concerns and the ways in which multi-disciplinary input impacted upon recovery both during the acute hospital phase and following discharge home. A comparative analysis between the 'usual care' and intervention focus groups will explore the impact of the intervention on participants' key issues and concerns.

Healthcare professionals

Using purposive sampling, we will invite 8–10 representatives from key healthcare disciplines at each site to participate in focus group interviews towards the end of

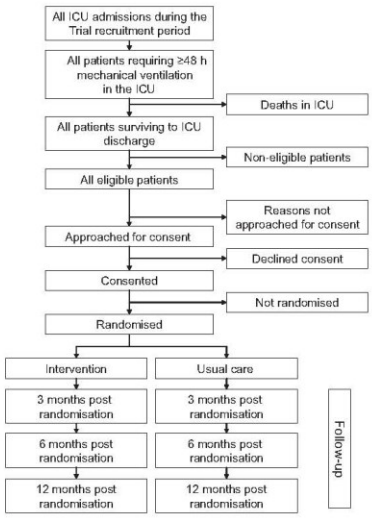

Figure 3 The CONSORT diagram that will be reported to account for all patients screened for eligibility, approached for consent, enrolled in the trial and followed up and the predefined time points. For each cell, the numbers of patients will be included. For the follow-up time points, the numbers of patients completing the various outcome measures will be recorded.

the recruitment period. Drawing upon our analysis of the research logs, participants will be invited to discuss barriers to the delivery and coordination of patient-led care among both groups and perceptions (including acceptability) of the GRAs as a novel strategy for the rehabilitation of patients after ICU discharge.

Assessment of research logs kept by GRAs

The GRAs will keep a log throughout the trial to record their experience of the novel role. Using thematic analysis, we will analyse these to categorise the principle barriers to the intervention and successful strategies in the implementation of the intervention both in individual patients and across ward and hospital settings. These data will supplement the quantitative measurement of process outcomes and facilitate the translation of findings into routine care.

Blood sampling for biomarker inflammation study

A substudy will investigate the prevalence of persisting inflammation following ICU discharge and its relationship with recovery. For patients who consent to additional blood sampling, a 10 ml blood sample will be collected at randomisation, weekly until hospital discharge and at the 3-month visit, and stored frozen as plasma and serum. Biological substances involved in the inflammatory response will subsequently be measured and related to measures of physical recovery.

Health economic evaluation

Cost-effectiveness will be estimated using a prospective within trial analysis of treatment effects analysed on an intention-to-treat basis and a decision model of long-term costs and health outcomes. The primary endpoint for the economic analysis will be incremental cost-effectiveness ratios comparing the intervention group with the usual standard of care impact, focusing on health service use and HRQoL. Health service costs will be assigned to the type and intensity of resource use measured by rehabilitation interventions/contacts, medications, hospital clinic attendances and hospitalisation episodes from randomisation to 12 months of follow-up. The health economic questionnaire used in the study is available of the ECTU website (http://www.clinicaltrials.ed.ac.uk). Unit costs will reflect a mixture of approaches including activity-based analyses of resource consumption for specific rehabilitation interventions alongside average per diem inpatient costs calculated on a specialty-specific basis using the Scottish Health Service Costs system. Endpoints for health effects will include survival times and quality-adjusted survival times. Quality-adjusted survival times per life years will be calculated for all randomised patients using the HRQoL measures. These within trial analyses will be integrated into a decision model of long-term costs and health effects. We propose to use a Monte-Carlo microsimulation model. Base case analysis, using the intention-to-treat results, and sensitivity analysis will be conducted by varying key model parameters and critical assumptions over plausible ranges/distributions. The decision model will also permit the analysis of cost-effectiveness conditional on prespecified patient subgroups to allow for heterogeneity in the case mix of patients receiving intensive care and their baseline condition at ICU discharge. A full description of the proposed analysis can be found in the full protocol on the RECOVER page of the ECTU website (http://www.clinicaltrials.ed.ac.uk).

RESEARCH GOVERNANCE

The trial will be carried out under the principle of the International Conference for Harmonisation of Good Clinical Practice guidelines. Specifically, the research sponsors' (Edinburgh University/Lothian Health Board) guidelines for adverse event reporting policy and Standard Operating Procedures will be followed. These are consistent with adverse event reporting guidelines from the National Research Ethics Service for safety reporting in research other than clinical trials of investigational medicinal products. A monitoring plan will be agreed with the sponsor early in the trial.

ETHICS

The trial has received a favourable ethical opinion by the Scotland A Research Ethics Committee (Ref 10/MRE00/18) and is approved by the NHS Lothian R&D department (Ref 2010/R/AN/02).

TRIAL MANAGEMENT

The trial will be managed by a Trial Management Group and overseen by a Trial Steering Group, which includes an independent Chairman, two independent clinical specialists, and a lay representative. A Data Monitoring and Safety Committee will monitor the progress, quality and safety of the trial. The membership of these committees is available on the RECOVER page of the ECTU website (http://www.clinicaltrials.ed.ac.uk). The trial registration number is ISRCTN: 09412438 and the trial is registered on the NIHR Clinical Research Network (Critical Care portfolio; number 8849).

RELATED STUDIES

RECOVER is part of a programme of work exploring rehabilitation needs and intervention strategies following critical illness. Two other studies (RELINQUISH study and EATEN study) will sample cases enrolled in the trial.

The RELINQUISH study (REcovery following critical illness: a Longitudinal Qualitative exploration of perceived healthcare and Support needs among survivors; developing timely interventions after Hospital discharge; NIHR portfolio number 9986) will invite up to 24 participants enrolled in the RECOVER trial to each take part in four interviews over the 12 months following ICU discharge. Purposive sampling will be used to enrol equal numbers from each of the RECOVER groups with representation from relevant subgroups according to age, gender, duration of mechanical ventilation, ward discharge destination, occupational status and level of social support. The study aims are to examine the ways in which perceived healthcare and support needs change over time, to assess the extent to which these needs are currently met by formal and informal community-based resources, to identify potential service improvements for survivors of critical illness throughout the recovery process following discharge into the community and to explore the impact of the RECOVER intervention upon the perceived healthcare and support needs of survivors following discharge into the community. RELINQUISH is funded by the Health Services Research Unit of NHS Lothian; the PI is Dr Pam Ramsay (coinvestigator for the RECOVER trial).

The EATEN study (An Exploration of the bArriers to nutritional intake after inTENsive care; NIHR portfolio number 10631) will invite up to 17 participants in the RECOVER study to participate in sequential hospital based interviews and field work, followed by an interview 3 months following ICU discharge. The study will explore the barriers to achieving nutritional recovery during this period of recovery and is funded as part of a dietetic PhD Fellowship for Judith Merriweather (coinvestigator for the RECOVER trial) by the Chief Scientist's Office, Scotland.

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Contributors The following is taken from the submitted manuscript. The initials refer to the listed co-authors: TSW, LGS, PR, JM and GH conceived the project and completed pilot and feasibility work. Specialist clinical input to protocol design was provided by TSW and SJM (critical care perspective), LGS (physiotherapy/rehabilitation), PR and JZR (nursing) and JM (dietetics). Statistical advice was provided by GDM and SL and the health economic evaluation designed by JF. The qualitative studies were conceived and designed by PR, GH and JZR. The inflammatory biomarker substudy was designed by TSW and DMG. Advice on health service reorganisation aspects was provided by SJM and GH. Advice on psychological outcomes and interventions was provided by AH and JZR. JB is trial manager. All authors contributed to the design of the final protocol and set-up of the trial.

Funding Funded by the Chief Scientists Office, Scotland (grant number CZH/4/53). Additional funding has been provided through the Edinburgh Critical Care Research Group.

Competing interests None.

Ethics approval Ethics approval was provided by Scotland A REC.

Provenance and peer review Not commissioned; internally peer reviewed.

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Appendix 8 Scotland A ethical approval

Scotland A Research Ethics Committee

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NHS SCOTLAND

Mrs Judith Merriweather
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Date: 1 March 2010
Your Ref.:
Our Ref.: 10/MRE00/10

Enquiries to: Walter Hunter
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Dear Mrs Merriweather

Study title: **A pilot study to explore the barriers to nutritional intake after intensive care**

REC reference: **10/MRE00/10**

The Scotland A Research Ethics Committee reviewed the above application at the meeting held on 25 February 2010. Thank you for attending to discuss the study.

Ethical opinion

The Committee noted this was a student pilot study as part of a PhD course, which would include adults lacking capacity among the proposed sample size of ten participants. The eligibility for inclusion would be patients in ICU who were ready for discharge either to a surgical or medical ward. However stroke and liver transplant patients would be excluded but the reason for this was not clear from the application. There was recognition that patients lost body weight during critical illness and therefore nutrition was important but a significant number of patients were discharged home without any rehab plans. The Committee's main ethical concern was the sample size and had reservations that ten participants would be sufficient to achieve a meaningful outcome. Given the small sample size the need for including adults lacking capacity was questioned. They wondered what impact the observation and recording of food intake would be on staff behaviour. The study also involved asking participants to recall intake but it was questionable how meaningful would this be when their memory may be affected. The Committee wondered also whether the interviews with staff would take place in the ward setting or outwith, possible during a break. They considered that taking staff out of the ward could prove challenging but equally a 20 minute interview in the ward presented problems. The application though did not clarify what questions that would be asked to justify the length of interview justify the length of interview. The Committee identified typographical errors in the documentation, which would need to be addressed.

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Dr Zealley welcomed Ms J Merriweather to the meeting. Ms Merriweather was asked what the next step was after the pilot ended. She indicated that she would like to do a bigger study possibly using 20 patients and explore what patients feel about their nutritional requirements. Ms Merriweather further explained that she was looking to prove that using food diaries would confirm that patients were not eating well. The interview process would establish the reasons why patients were not eating well. Ms Merriweather was asked to justify the inclusion of adults lacking capacity. In response she explained that from previous studies there was evidence to support the view that patients unable to communicate on their own behalf fared worse than those who had capacity to speak up. She was also asked what proportion of participants would lack capacity but was unable to say but the intention was to include patients who had different variations of need including those unable to feed themselves. Ms Merriweather was asked about the extent of staff involvement. She indicated that the interviews would be very short in duration; the maximum time would be around 20 minutes but in reality most of the interviews would last around 5-10 minutes. Ms Merriweather further confirmed that the interviews would take place in the ward.

After Ms Merriweather left the meeting the Committee considered that there was no connection between this pilot study and the proposed next study. They considered therefore that a sample size of ten was insufficient for a study that was no longer a pilot; for example, a more appropriate size would be twenty having 10 participants from those discharged to surgical wards and 10 to medical wards.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Adults with Incapacity (Scotland) Act 2000

I confirm that the Committee has approved this research project for the purposes of the Adults with Incapacity (Scotland) Act 2000. The Committee is satisfied that the requirements of section 51 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

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Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

The Committee specified the following conditions, which should be undertaken before the study commences:

- Both information sheets need proof reading since 'you' and 'your relative are mixed wrongly to the extent that the patient was asked if their relative has problems with eating!

The Committee would be grateful for a copy of the final version of the participant information sheet for their information. You should also provide the signed declaration pages from the application form.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

The Committee also made the following observation:

- There was no obvious connection between this study and the study that would follow; a sample size of 20 would be more likely to develop a more robust tool.

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Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter		08 January 2010
REC application		05 January 2010
Protocol	2.0	06 January 2010
Investigator CV: Mrs J Merriweather		06 January 2010
Investigator CV: Professor T Walsh		
Participant Information Sheet: Participant	2	06 January 2010
Participant Information Sheet: Relative	1	06 January 2010
Participant Consent Form: Participant	1	06 January 2010
Participant Consent Form: Relative	1	06 January 2010
GP Letter: Participant	1	06 January 2010
GP Letter: Relative	1	06 January 2010
Interview Schedules/Topic Guides	1	06 January 2010

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

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The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

REC reference number: 10/MRE00/10-Please quote this number on all correspondence

Yours sincerely

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Our Ref.: 10/MRE00/10

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Dear Mrs Merriweather

Study title: **A pilot study to explore the barriers to nutritional intake after intensive care**

REC reference: **10/MRE00/10**

Thank you for your letter of 23 March 2010. I can confirm the Scotland A REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 1 March 2010. Please note these documents are for information only and have not been reviewed by the committee.

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Participant Information Sheet: Participant	3	23 March 2010
Participant Information Sheet: Relative	2	23 March 2010

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

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REC reference number: 10/MRE00/10-Please quote this number on all correspondence

Yours sincerely

Walter Hunter
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03 August 2010

Mrs Judith Merriweather
Dietician
NHS Lothian
Dietician
Room GU309
Chancellors Building
Royal Infirmary of Edinburgh
EH16 4SB

Dear Mrs Merriweather

Study title:	**A pilot study to explore the barriers to nutritional intake after intensive care.**
REC reference:	**10/MRE00/10**
Amendment date:	**15 July 2010**

The above amendment was reviewed by Scotland A Research Ethics Sub-Committee meeting, held in correspondence on 2nd August 2010.

Favourable Opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

NHS
SCOTLAND

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter		17 July 2010
Notice of Substantial Amendment (non-CTIMPs)		15 July 2010
Participant Consent Form	V2	08 July 2010
Participant Information Sheet	V4	08 July 2010
Protocol	V3	08 July 2010

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

10/MRE00/10: ***Please quote this number on all correspondence***

Appendix 9 Information sheets and consent forms

Exploration of the Barriers to Nutritional Intake After Intensive Care

Patient Information Sheet – Part 1

You are being invited to consider whether you would like to take part in a research study. Before you decide whether you would like to take part it is important for you to understand why the research is being done and what it involves. Please take your time to read the following information carefully. Talk to others about the study if you wish.

- *Part 1 tells you the purpose of this study and what will happen if you took part.*
- *Part 2 gives you more detailed information about how the study will be conducted.*

Ask if there is anything that is not clear or if you would like further information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

You have been critically ill and received treatment on the intensive care unit (ICU). As you are starting to get better the staff are planning your discharge to the ward. We know that patients often experience problems with eating and have a poor appetite when they go to the ward. We want to find out exactly what these problems are so that we can find ways to help patients eat better after they have been in intensive care.

In this study we will observe patients on the ward at meal times to identify problems with food delivery. We will also ask you if you have experienced any problems with eating.

Why have I been chosen?

The research study is looking at people who have spent more than two days on a ventilator (breathing machine) in the intensive care unit. As you were on the ventilator for more than two days care we have approached you to see whether you would consider taking part in the study.

Do I have to give permission to take part?

No. It is up to you to decide whether or not you want to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are free to withdraw from the study at any time and without giving reason. A decision to withdraw at any time, or a decision not to take part, will not affect your care.

What happens in the study?

If you agree to take part in the study you will be involved in the study from the time you are transferred to the ward until 3 months after you were discharged from ICU.

The researcher will visit the ward regularly and collect information from your medical and nursing notes relating to any problems you might have had with eating. We will observe you around meal times to see how you are managing with eating and record your food intake in a diary. The researcher will also ask you some questions about your appetite, how you feel you are getting on and ways you think might help improve your eating. These short interviews will be digitally recorded. These interviews will continue by phone after you are discharged from hospital until 3 months after you were discharged from ICU, and you

will be asked to complete a diary of what you eat. One final interview will be arranged at 3 months after your discharge from ICU. This will be done either in your own home or you can come to the hospital if you prefer.

What are the possible benefits of taking part?

The purpose of this study is to try and find out why patients do not always manage to eat well after being in intensive care. By taking part in the study it will hopefully provide information that will help future patients who are in a similar situation to yourself.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible you suffer will be addressed. Detailed information about this is given in part 2.

Will taking part in the study be kept confidential?

Yes. All information about you will be handled in the strictest of confidence. More details are given in part 2.

IF YOU ARE CONSIDERING GIVING CONSENT TO TAKE PART, PLEASE READ THE ADDITIONAL INFORMATION IN PART 2 BEFORE MAKING A DECISION

Part 2 – Additional details about this study

What happens if I want to be withdrawn from the study?

You can change your mind and ask to be withdrawn from the study at any time if you wish and this will not affect your treatment in any way.

If you wish to withdraw from the study we would like to use any data collected while you were participating in the study if you had no objections.

What if there is a problem?

If you have a concern about any aspect of this study, ask to speak to the researcher who will answer any questions you may have. If you remain unhappy and wish to complain formally, you can do this through the NHS complaints Procedure. Details can be obtained from the complaints department at Edinburgh Royal Infirmary (0131 242 3382).

How will the information collected be dealt with?

If you give permission to take part, some parts of your medical records and the data collected for the study will be looked at by authorised persons involved in the research. They may also be looked at by people from the Research and Development Office to check that the study is being carried out correctly.

Will my family doctor/general practitioner know about this study?

Yes. We will write to your general practitioner/family doctor to tell them about the study and inform them you have taken part.

What will happen to the results of the study?

The results of this study will be used to inform a subsequent study and will be reported to members of staff in the hospital and may be presented at research conferences. If you wish we can send you a summary of the results after the study is completed.

Who is organising and funding the research?

The research is sponsored by NHS Lothian and has been funded as part of a PhD fellowship from the Chief Scientist Office.

Who has reviewed the study?

This study has been given a favourable ethical opinion for conduct in the NHS by the multi-centre research ethics committee.

Further information about this study

If they would like any further information or to discuss any issues relating to this study you can contact the research dietitian (Judith Merriweather 0131 242 6394) who is carrying out this research.

Thank you for taking the time to read this information.

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Exploration of the Barriers to Nutritional Intake After Intensive Care

Relative Information Sheet – Part 1

You are being invited to consider whether you would like your relative to take part in a research study. Before you decide whether you would like them to take part it is important for you to understand why the research is being done and what it involves. Please take your time to read the following information carefully. Talk to others about the study if you wish.

- *Part 1 tells you the purpose of this study and what will happen if your relative took part.*
- *Part 2 gives you more detailed information about how the study will be conducted.*

Ask if there is anything that is not clear or if you would like further information. Take time to decide whether or not you wish for them to take part.

What is the purpose of the study?

Your relative has been critically ill and has received treatment on the intensive care unit. As they are now starting to get better the staff are planning their discharge to the ward. We know that patients often experience problems with eating and have a poor appetite when they go to the ward. We want to find out exactly what these problems are so that we can find ways to help patients eat better after they have been in intensive care.

In this study we will observe patients on the ward at meal times to identify problems with food delivery. We will also ask your relative if they have experienced any problems with eating.

Why has my relative been chosen?

The research study is looking at people who have spent more than two days on a ventilator (breathing machine) in the intensive care unit. As your relative was on the ventilator for more than two days care we have approached you to see whether you would consider letting them take part in the study.

Do I have to give permission for my relative to take part?

No. It is up to you to decide whether or not you want them take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are free to withdraw your relative from the study at any time and without giving reason. A decision to withdraw at any time, or a decision not to take part, will not affect their care.

As soon as possible we will ask your relative whether they would like to continue in the study. If your relative decides not to continue in the study they will not be required to do so. In no way will this decision then affect their care.

What happens in the study?

If you agree that your relative can take part in the study they will be involved in the study from the time they are transferred to the ward until they are discharged from hospital.

The researcher will visit the ward regularly and collect information from your relative's medical and nursing notes relating to any problems they might have had with eating. We will observe your relative around meal

times to see how they are managing with eating and also ask them some questions about their appetite and ways they think might help improve their eating.

What are the possible benefits of taking part?

The purpose of this study is to try and find out why patients do not always manage to eat well after being in intensive care. Your relative taking part in the study will hopefully provide information that will help future patients who are in a similar situation.

What if there is a problem?

Any complaint about the way your relative has been dealt with during the study or any possible harm they might suffer will be addressed. Detailed information about this is given in part 2.

Will taking part in the study be kept confidential?

Yes. All information about your relative will be handled in the strictest of confidence. More details are given in part 2.

IF YOU ARE CONSIDERING GIVING CONSENT FOR YOUR RELATIVE TO TAKE PART, PLEASE READ THE ADDITIONAL INFORMATION IN PART 2 BEFORE MAKING A DECISION

Part 2 – Additional details about this study

What happens if I want my relative to be withdrawn from the study?

You can change your mind and ask for your relative to be withdrawn from the study at any time if you wish and this will not affect their treatment in any way.

If you wish for them to withdraw from the study we would like to use any data collected while they were participating in the study if you had no objections.

What if there is a problem?

If you have a concern about any aspect of this study, ask to speak to the researcher who will answer any questions you may have. If you remain unhappy and wish to complain formally, you can do this through the NHS complaints Procedure. Details can be obtained from the complaints department at Edinburgh Royal Infirmary (0131 242 3382).

How will the information collected about my relative be dealt with?

If you give permission for your relative to take part, some parts of their medical records and the data collected for the study will be looked at by authorised persons involved in the research. They may also be looked at by people from the Research and Development Office to check that the study is being carried out correctly.

Will my relative's family doctor/general practitioner know about this study?

Yes. We will write to your relative's general practitioner/family doctor to tell them about the study and inform them that your relative has taken part.

What will happen to the results of the study?

The results of this study will be used to inform a subsequent study and will be reported to members of staff in the hospital and may be presented at research conferences. If you wish we can send your relative a summary of the results after the study is completed.

Who is organising and funding the research?

The research is sponsored by NHS Lothian and has been funded as part of a PhD fellowship from the Chief Scientist Office.

Who has reviewed the study?

This study has been given a favourable ethical opinion for conduct in the NHS by the multi-centre research ethics committee.

Further information about this study

If they would like any further information or to discuss any issues relating to this study you can contact the research dietitian (Judith Merriweather 0131 242 6394) who is carrying out this research.

Thank you for taking the time to read this information.

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Exploration of the Barriers to Nutritional Intake After Intensive Care

Patient Consent Form

Name of Researcher: Judith Merriweather

	Please initial box
1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions/ ask for clarification.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	☐
3. I understand that sections of my medical notes may be looked at by the researchers conducting this study where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.	☐
4. I understand that all information will be anonymised by the allocation of codes and that information will remain confidential and only be used for research.	☐
5. I agree to my interviews being digitally recorded	☐
6. I agree to take part in the above study.	☐
7. I agree for the researcher to inform my GP of my participation in the study.	☐

_____	_____	_____
Name of Person giving consent	Date	Signature
_____	_____	_____
Name of Person taking consent (if different from researcher)	Date	Signature
_____	_____	_____
Researcher	Date	Signature

1 copy for patient; 1 for researcher; 1 to be kept with hospital notes

Judith Merriweather. Exploration of the Barriers to Nutritional Intake after Intensive Care. Consent Form. Version 2 08/07/10

Exploration of the Barriers to Nutritional Intake After Intensive Care

Relative Consent Form

Name of Researcher: Judith Merriweather

Please initial box

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions. ☐

2. I confirm that I am the nearest relative or welfare guardian for _____and that no other welfare guardian or nearest relative exists. ☐

3. I understand that my relative's participation is voluntary and that I am free to withdraw him/her at any time, without giving any reason, without my relatives medical care or legal rights being affected. ☐

4. I understand that my relative is the patient being studied and that sections of their medical notes may be looked at by the researchers conducting this study where it is relevant to the research. I give permission for these individuals to have access to their records. ☐

5. I understand that all information about my relative will be anonymised by the allocation of codes and that information will remain confidential and only be used for research. ☐

6. I agree for my relative to be involved in the above study understanding that they will be asked to give their own consent as soon as they are able. ☐

7. I agree for the researcher to inform my relative's GP about their participation in the study ☐

_____ _____ _____

Name of Person giving consent Date Signature

Please indicate if you are the welfare guardian / nearest relative (Please circle as appropriate). If you are the nearest relative please indicate the degree of kinship to the participant _____

_____ _____ _____

Name of Person taking consent (if different from researcher) Date Signature

_____ _____ _____

Researcher Date Signature

Appendix 10 Summary of oral and poster presentations undertaken by researcher

Poster presentations (Poster example on p397)

June 2010 – NHS Lothian What's New in ICU Conference, Edinburgh

October 2011 – Australian and New Zealand Annual Scientific Meeting on Intensive Care (ANZIC), Brisbane

May 2012 – NHS Lothian Delivering Better Care Conference, Edinburgh

Oral presentations

June 2011 - UK Critical Care trials forum, Edinburgh

September 2011 Scottish Intensive Care Society Meeting, Stirling

June 2012 – UK Critical Care trials forum, Belfast

September 2012 Scottish Intensive Care Society Meeting, Stirling (Awarded Nurses, Midwifes and Allied Health Professionals prize for best research paper)

November 2012 – Lecture for the Critical Care Module, BN Nursing Students, University of Edinburgh

To eat or not to eat: Barriers to nutritional recovery after Intensive Care

Judith Merriweather[1], Tim Walsh[2], Lisa Salisbury[3]

[1]PhD Student, The University of Edinburgh & Critical Care Dietitian, Royal Infirmary of Edinburgh
[2]Professor of Critical Care, Clinical and Surgical Sciences, The University of Edinburgh
[3]Research Fellow, Nursing Studies, The University of Edinburgh

"I've no appetite, very little in the way of taste buds"
(interviewee 002)

"I'm at a low stage at the minute, food is the last thing on my mind"
(interviewee 008)

Background

Survivors of critical illness suffer from a range of problems affecting physical, psychological, and social well-being which result in a high prevalence of low reported Health Related Quality of Life for many months after ICU discharge (1). The term "post-ICU syndrome" has been coined, which includes psychological problems such as anxiety, depression, and post-traumatic stress reactions in 10-40% of patients at 3-6 months (2). Physical problems include a range of symptoms such as fatigue, reduced appetite, altered taste, joint stiffness, pain, breathlessness, and muscle weakness. Research has shown that prolonged ICU stay results in wasting of lean tissue, particularly muscle mass, at up to 2% each day, most likely from a combination of muscle catabolism and atrophy secondary to neuropathic degeneration(3). These factors, combined with a significant prevalence of pre-admission nutritional problems due to co-morbidity, result in a high incidence of malnutrition following ICU discharge.

Although many studies have addressed nutritional issues during ICU stay, there is remarkably little dietetic specific research during rehabilitation. Few studies have systematically and comprehensively explored the barriers to nutritional recovery or ways to overcome them.

Aim

To explore patients perspective of the factors that determine nutritional intake at ward level. The relationship between their perspective and the provision of food and their intake and the organisation factors which underlie these patterns will also be examined.

Research Questions

- How do patients experience eating and food in relation to their recovery from critical illness?
- What are the barriers to nutritional intake during the ward phase of care?

Method

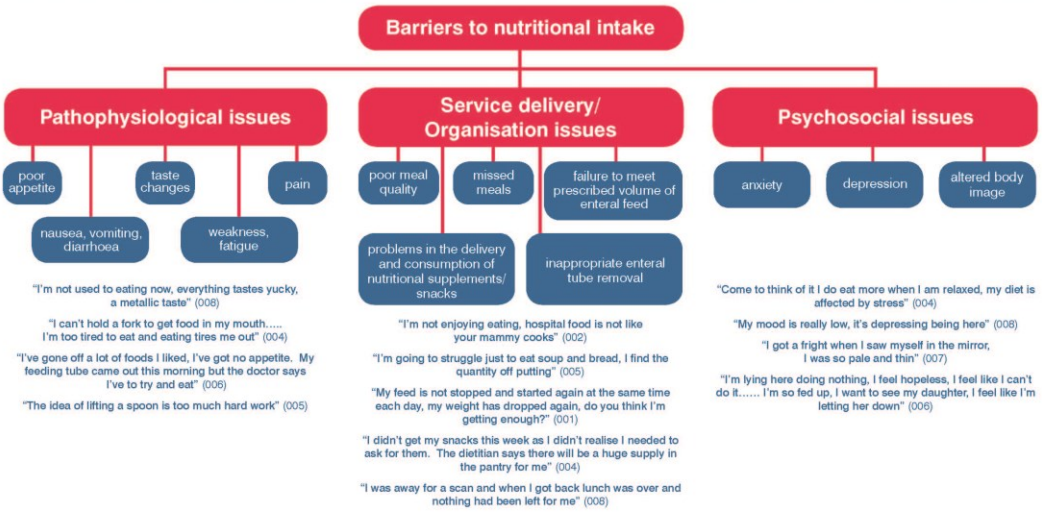
Eight patients were recruited on discharge to the ICU, who had required greater than 48 hours of mechanical ventilation. Interviews were carried out on discharge from ICU then weekly until hospital discharge. Observation of ward practice, including meal times was also undertaken.

Findings

Demographic details of patients

	Patients (n=8) Mean (SD)
Gender	5 male : 3 female
Age (years)	55.5 (17.5)
APACHE II score	20.6 (5.3)
Ventilation days	22.0 (17.3)
Length of ICU stay (days)	26.7 (18.6)
Ward destination	5 surgical ward, 3 medical ward
Length of ward stay (days)	28.5 (19.1)

The key issues that emerged were grouped under the following:



References

1. Jones C, Skirrow P, Griffiths RD, Humphris GH, Ingleby S, Eddleston J et al. Rehabilitation after critical illness: A randomized, controlled trial. Critical Care Medicine 2003; 31(10):2456-2461.
2. Cuthbertson BH Hull A Strachan M Scott J (2004) Post-traumatic stress disorder after critical illness requiring general intensive care. *Intensive Care Medicine* 30 (3) 450-455.
3. Griffiths RD Jones C (1999) ABC of intensive care - Recovery from intensive care *British Medical Journal* 319 (7207) 427-429.

Implications

This preliminary study identified a wide range of barriers to nutritional recovery at ward level. Ongoing prospective work is exploring the long term impact of these barriers on nutritional recovery. This will then allow the development of a model of care that will improve current management of nutrition for patients recovering from critical illness.

Work funded by the Chief Scientist Office

Appendix 11 Publications from study

Journal of Clinical Nursing

ORIGINAL ARTICLE

Nutritional rehabilitation after ICU – does it happen: a qualitative interview and observational study

Judith Merriweather, Pam Smith and Timothy Walsh

Aims and objectives. To compare and contrast current nutritional rehabilitation practices against recommendations from National Institute for Health and Excellence guideline Rehabilitation after critical illness (NICE) (2009, http://www.nice.org.uk/cg83).
Background. Recovery from critical illness has gained increasing prominence over the last decade but there is remarkably little research relating to nutritional rehabilitation.
Design. The study is a qualitative study based on patient interviews and observations of ward practice.
Methods. Seventeen patients were recruited into the study at discharge from the intensive care unit (ICU) of a large teaching hospital in central Scotland in 2011. Semi-structured interviews were conducted on transfer to the ward and weekly thereafter. Fourteen of these patients were followed up at three months post-ICU discharge, and a semi-structured interview was carried out. Observations of ward practice were carried out twice weekly for the duration of the ward stay.
Results. Current nutritional practice for post-intensive care patients did not reflect the recommendations from the NICE guideline. A number of organisational issues were identified as influencing nutritional care. These issues were categorised as ward culture, service-centred delivery of care and disjointed discharge planning. Their influence on nutritional care was compounded by the complex problems associated with critical illness.
Conclusions. The NICE guideline provides few nutrition-specific recommendations for rehabilitation; however, current practice does not reflect the nutritional recommendations that are detailed in the rehabilitation care pathway.
Relevance to clinical practice. Nutritional care of post-ICU patients is problematic and strategies to overcome these issues need to be addressed in order to improve nutritional intake.

Key words: clinical practice, grounded theory, interviews, nutrition, observation, rehabilitation

Accepted for publication: 20 December 2012

Background

Malnutrition affects every organ system resulting in reduced gastrointestinal (Winter *et al.* 2000), mental (Brozek 1990) and endocrine (Schwartz & Seeley 1997) function and recovery. It has also been shown to impair wound healing (Allison 2000) and increase the risk of infection (Lean & Wiseman 2008). Ultimately, malnutrition has a detrimental effect on recovery from disease and is associated with a significantly higher incidence of complications and mortality (Correia & Waitzberg 2003).

Malnutrition also has financial implications as malnourished patients have higher hospitalisation costs, on average 24% higher than those who are well nourished (Lim *et al.* 2012). These costs are due to longer hospital stays, which are around 1·5 times longer than well-nourished patients (Lim

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et al. 2012), increased use of hospital resources costing the NHS £6000 per patient over a six-month period (Guest *et al.* 2011) and higher readmission rates (Lean & Wiseman 2008).

The prevalence of malnutrition in hospitalised patients has been well documented with early studies reporting a prevalence of 20 50% in medical and surgical patients (Bistrian *et al.* 1976, Hill *et al.* 1977). More recent studies have continued to highlight the prevalence of malnutrition among acute care patients across the UK (Edington *et al.* 2000, Kelly *et al.* 2000, Ruxton *et al.* 2008). One of the few studies that have looked at the prevalence of malnutrition in the intensive care unit (ICU) found that 43% of patients were malnourished (Giner *et al.* 1996).

Malnutrition as a result of critical illness has been defined as 'acute disease or injury-related malnutrition', which is associated with severe, acute inflammation (Jensen *et al.* 2010). During periods of critical illness, the inflammatory response elevates energy expenditure and nitrogen excretion that is only partially attenuated by the provision of nutritional support (Zoico & Roubenoff 2002). Contributing to this weight loss is inadequate nutritional intake with ICU patients only receiving 60 80% of their prescribed energy and protein requirements (Engel *et al.* 2003, Binnekade *et al.* 2005, Reid 2006, Cahill *et al.* 2010). These suboptimal intakes result from delays in initiating feeding (Wandrag *et al.* 2011) and feed interruptions due to nausea, vomiting, abdominal distension, large gastric aspirates, tube displacement, investigations and prolonged fasting for procedures (Heyland *et al.* 2003, Reid 2006).

Oral diet following extubation from mechanical ventilation has also been shown to be inadequate. Peterson *et al.* (2010) assessed the oral intake of 50 patients for the first seven days after extubation and found that mean energy and protein intake was <50% of estimated requirements on all seven days of the study period. The authors identified a number of factors that may be associated with inadequate nutritional intake in extubated patients, including weakness, gastrointestinal disturbances, anorexia, lack of nutritional knowledge by healthcare professionals and instigation of a therapeutic diet, for example low fat, puree or renal diets.

A report by the Council of Europe identified a number of organisational factors affecting nutritional care (Beck *et al.* 2002). These included ambiguity over responsibility for nutritional care; lack of nutritional education for nurses and doctors; lack of nutritional information given to patients; poor communication between healthcare professionals; and failure of hospital management to engage with nutritional care.

For patients after critical illness, nutrition plays an important role in the recovery process.

Griffiths (2002, p. 48) stated that '*the period following intensive care is characterized by anabolism, remodelling, restoration and redistribution of the body composition. This is not possible without an adequate nutrient delivery. The right foods are important, but the challenge is not in recognizing the need for adequate nutrition but in enabling the desire, delivery and ability to eat over the prolonged period of rehabilitation*'.

In 2009, the National Institute of Clinical Excellence guideline highlighted the need to improve rehabilitation for this patient group, although the guidelines were based largely on expert opinion (NICE 2009). There is a lack of research exploring nutritional rehabilitation following critical illness as reflected in the limited guidance in the NICE guideline. Post-ICU patients are nutritionally at risk as a result of the effects of critical illness and inadequate nutritional intakes within the ICU. Further research in nutritional rehabilitation after critical illness is clearly required.

Aim

This paper will examine the organisational issues that influence nutritional care for patients after discharge from ICU and identify any problems specific to this patient group. It will then compare the issues identified with the nutritional rehabilitation recommendations within the NICE (2009) guideline.

Method

Grounded theory was the methodology used to underpin the study. This is a methodology that was described by Strauss and Corbin as '*theory that was derived from data, systematically gathered and analysed through the research process*' (Strauss & Corbin 1998, p. 12). In essence, grounded theory provides systematic guidelines for the collection and analysis of data in order to develop theory that is grounded in the data itself. The researcher employed Symbolic Interactionism as a theoretical perspective, a position usually adopted for studies using grounded theory (Bulmer 1969). The premise of this philosophy is that humans construct meanings, and interactions with others shape these meanings (Bulmer 1969). Adoption of this philosophy was appropriate for examining and understanding interactions in the patient's world.

Setting

The setting for the study was a large teaching hospital in central Scotland. The ICU, where patients were recruited from, is classed as a general ICU, which means that the population would comprise of a full case mix profile, as

recommended in the NICE (2009) guideline. This location was chosen due to the size of the unit, which would ensure sufficient numbers for the study. It is also where the researcher is currently employed so access and recruitment of patients on discharge from ICU was aided.

Participants

Eligible patients were those who had had more than two days of mechanical ventilation in ICU and were ready for discharge to a ward. Patients were excluded if they were going to be discharged to pre-existing ward-based rehabilitation programmes, for example following a stroke or liver transplant.

Seventeen patients were recruited to the study. Judgemental or purposive sampling was employed to select patients with the aim to recruit male and female patients, patients under the age of 65 or over 65 and those being discharged to either surgical or medical wards.

Data collection

Observation

In this study, the researcher visited the patient on the ward twice a week and information relating to nutritional intake was noted from medical and nursing notes. The researcher observed breakfast, lunch and dinner times at different points during the patient's ward stay. Field notes were used to collate the data gathered from observations.

Interviews

Short semi-structured interviews were carried out with patients at the time of transfer to the ward and weekly thereafter for the duration of the ward stay. These interviews were brief, out of necessity, as the patients were easily fatigued and the researcher did not want the interviews to become unnecessarily onerous. The interview questions focussed on identifying factors that influenced nutritional intake during the ward phase of care.

A further interview was carried out at three months post-ICU discharge. This was undertaken either at the patient's home or in the Clinical Research Facility, according to patient preference. These interviews were semi-structured and an interview guide was used to help focus the interviews on three main topics identified from previous exploratory work: experiences of recovery after critical illness, effect of recovery on nutritional intake and identification of factors that influenced nutritional intake. The 30- to 70-minute interviews were digitally recorded and transcribed verbatim.

Rigour

In order to produce credible research, there is a need to '*accurately reflect the phenomena under study as perceived by the study population*' (Lewis and Ritchie (2003, p. 274). In an effort to ensure credibility, the study sample included patients of different genders, age ranges and diagnoses in order to be representative of a general ICU patient population. In addition, two patients were asked to provide feedback on the study findings to ascertain whether the researcher had represented them appropriately. The dependability of the researcher's findings has been strengthened by her affinity with the study setting as this served to enhance observer insight. As the researcher was recognised on the wards as a clinical dietitian rather than a researcher, this proved advantageous as known observers have the greatest freedom to be able to observe, listen and question (Loftland & Loftland 1995).

Analysis

Action coding involving a line-by-line analysis of the data from the interviews was undertaken as described by Charmaz (2006). Incident-to-incident coding was then conducted for the observational data. The process of constant comparison was then used to establish analytic distinctions (Glaser & Strauss 1967). From this, focussed coding was used to synthesise the data and theoretical categories were developed. Theoretical memos played an integral part in the analysis process, promoting researcher reflexivity and transparency in the research process (Charmaz 2006).

Ethical approval

All patients received both oral and written information and gave their informed consent to participate. If the patient was unable to give their own consent, consent was sought from the patient's nearest relative or welfare guardian. When the patient became competent to give consent, their informed consent was obtained. Patients and relatives were also assured confidentiality and anonymity. The study was approved by the Scotland A Research Ethics Committee.

Results and discussion

The theoretical codes that emerged from the data were ward culture, system-centred delivery of care and disjointed discharge planning. These relate to the core category 'the impact of the organisation on nutritional care' (Fig. 1).

The findings from the study are presented and discussed in three sections relating to the specific time points identified in the NICE guideline (2009). The time points are before discharge from critical care; during ward stay; and before discharge to home or community care.

Before discharge from critical care

The NICE guidance states that healthcare professionals should '*ensure that the transfer of patients and the formal structured handover of their care are in line with "Acutely ill patients in hospital" (NICE clinical guideline 50). This should include the formal handover of the individualised, structured rehabilitation programme*' (NICE 2009, p. 10). The NICE clinical guideline 50 states that:

> The formal structured handover of care should include
>
> a plan for ongoing treatment, including drugs and therapies, nutrition plan, infection status and any agreed limitations of treatment. (NICE 2007, p. 14)

Observation of current practice demonstrated that limited nutritional documentation was provided on transfer from ICU to the ward. A verbal handover was given by the ICU nurse which included the current route for nutrition and whether the patient had commenced oral intake.

However, neither method of handover included the identification of a nutrition plan as recommended in the NICE clinical guideline (2007).

Observation of ward practice demonstrated that the general ward ethos was to remove any lines, tubes and catheters as soon as possible. This was reflected in the number of nasogastric (ng) tubes that were removed within the first 48 hours of the patient arriving on the ward. Nine of the seventeen patients were transferred to the ward with an ng tube *in situ*. Six of these tubes were removed within 48 hours of arrival on the ward on the advice of medical staff, prior to any formal assessment of nutritional intake by a dietitian. It is postulated that lack of a clearly identified nutritional plan, compounded with the noted influences of ward culture, could have been responsible for subsequent alterations to nutritional care.

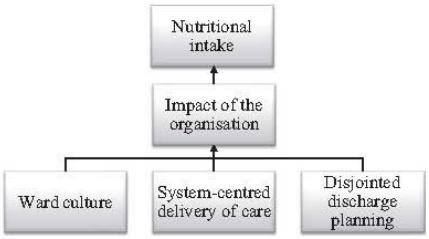

Figure 1 Organisational factors that influence nutritional intake.

The documented rationale for removal of these six tubes included 'ng feed stopped to allow diet to grow', 'ng out, push full diet', 'ng out to encourage eating and drinking'. However, observations showed that oral intake was minimal after the tube was removed. Loss of appetite and early satiety are associated with the anorexia of acute illness (Lennie 1999), and previous research has shown that post-ICU patients consume less than 50% of their nutritional requirements in the first week after extubation (Peterson *et al.* 2010).

It was also noted that 8 of the 17 patients in the study were transferred from ICU out with normal working hours due to bed pressures within the ICU. It is well recognised that out of hours transfers from ICU are associated with a poorer outcome than those discharged during the day (Goldfrad & Rowan 2000). The rationale for the deleterious effects of night transfers include reduced time for the patient to adjust to leaving the ICU, poorer-quality medical and nursing handovers due to the pressured nature of the discharge, reduced staffing levels at night and no available support from multidisciplinary team such as physiotherapist or dietitian (Carr 2002). Observations from the study revealed that medical decisions to remove many of the ng tubes were made out of hours when there was no dietetic presence to prevent this from happening.

It was clear from the study that lack of nutritional knowledge, particularly about the complex nutritional needs of the post-ICU patient, resulted in enteral nutrition being discontinued earlier than necessary, failure to identify ongoing nutritional problems and incorrect information relating to nutritional intake being recorded in the medical notes. This lack of medical knowledge about nutrition is a well-recognised problem (Parker *et al.* 1992) and led to a report from the Royal College of Physicians that highlighted the need to educate doctors in order to improve their recognition and management of nutritional issues (Royal College of Physicians 2002). However, despite the recommendations from the report, it is apparent that medical undergraduate training has not addressed this gap in education and doctors still fail to recognise the importance of nutrition in clinical practice.

During ward-based care

The NICE (2009) do not include any specific recommendations for nutritional rehabilitation during ward-based care.

However, the findings from this study demonstrated that a system-centred approach to care was adversely affecting the efficacy of nutritional care.

Food service times

Many patients highlighted issues around set mealtimes and the timing of the meal service. Some patients were unaccustomed to having three meals a day as their usual eating patterns were irregular or consisted of small, frequent snacks. Others struggled to eat a main meal at lunch time as they were used to having a light snack in the middle of the day. Another issue related to the timing of meals as patients reported that they found breakfast very early and the evening meal was also served much earlier than they were accustomed to. The quotes below illustrate these points:

> You know this sort of breakfast, lunch, supper, I mean that's just not for me you know, I sort of ate when I felt like it. But this regimental … well it's far too early for breakfast but I force myself you know, getting a cooked thing stuck in front of your face at 12 o'clock midday, it's just a, it's a struggle. (Patient 5)

> (My wife goes to the canteen) and I have my main meal at 6ish so I pushed it back and I found that a lot better … (hospital meals are) the wrong time, you know I can't get my head around that you have your main meal at 5 o'clock. Now I understand the reasons why, I'm not stupid, they can't base their meal regimen around me. But it is a main part, it has a big impact on me. (Patient 4)

Mealtimes are dictated by the organisation and are structured in order to facilitate hospital routine; however, this system is not necessarily beneficial for the patient. Naithani *et al.* (2008) identified meal serving times as an organisational barrier to eating in an observational study of hospital inpatients' experiences of access to food. Patients reported that meals were served at times that were different to their usual routine and also commented on the lack of snacks available between meals, which resulted in them feeling hungry, particularly in the evening as the evening meal was served so early. Another study by Kowanko *et al.* (1999) demonstrated that nursing staff were aware of these issues, yet failed to offer additional snacks.

For the post-ICU patient, many of whom suffer from a range of physiological issues as a result of critical illness, the identified problems relating to the structure of mealtimes and timing of hospital meals are particularly relevant. Post-ICU patients who experienced problems with early satiety struggled to consume sufficient quantities of food from a meal service system that only provided meals thrice daily. Another common problem after critical illness is loss of appetite (Griffiths 2002). Mealtimes where three courses were served at once was a disincentive to eating for patients with poor appetites.

System failures protected mealtimes

Protected mealtimes was an initiative introduced in 2004 as part of the Better Hospital Food Programme (DOH 2004). The purpose of a Protected Mealtime Policy is to create a time where all ward-based activities cease, provide an environment that is conducive to eating and release staff to aid patients who need assistance at mealtimes (Hospital Caterers Association 2004). Implementation of this policy had improved mealtimes as a result of fewer interruptions by healthcare professionals or relatives (Davidson & Scholefield 2005).

However, the Protected Mealtime Policy is not always adhered to and studies have demonstrated that patients still experience disruptions at mealtimes (Department of Health 2007). This study supports these findings with patient accounts describing occasions where meals were interrupted or missed completely. Missed meals were a result of the patient being off the ward for a clinical investigation or procedure, usually over lunch time. A study by Horan and Coad (2000) also identified the midday meal as the most commonly missed meal, which can result in a significant reduction in daily nutritional intake, particularly if lunch is the main meal of the day (O'Regan 2009).

Another problem with protected mealtimes is that relatives are excluded from visiting during this time and this results in the loss of the associated benefits of social interaction around mealtimes (Taylor 2008). Relatives are also unable to provide assistance with eating or offer encouragement to aid intake.

Observations showed that a number of the post-ICU patients required assistance with feeding due to the debilitating effects of critical illness. The researcher witnessed several conversations between nursing staff who were discussing the high level of care required for their post-ICU patient and expressing their concerns that the patient was 'too dependent' and 'lazy'. Patients were also perceived as being 'demanding' and 'precious'.

The researcher argues that nurses' attitudes towards post-ICU patients are constructed from negative stereotypes. The post-ICU patient also presents an additional conundrum as they do not fit the classic stereotype of a frail older patient where the need to assist with feeding is well recognised (Campbell 1993, Wright *et al.* 2008, Webster & Healy 2009). The post-ICU patient requires a high level of nursing care although half of the patients in the study were of working age (18 65), the youngest being 20 years old, and

this age group does not usually require assistance with eating.

A study by Coudin and Alexopoulos (2010) showed that patients' behaviour may be affected by nurses' attitudes, which serves to strengthen their previously held stereotypical views.

While Coudin and Alexopoulos's work was undertaken with older patients, the researcher argues that parallels can be drawn with the current study as both groups have complex needs and require high levels of nursing care, yet are cared for in a system that operates with high levels of specialism and short hospital stays.

McLafferty and Morrison (2004) identified that lack of education was a precursor to stereotyping. The researcher postulates that lack of knowledge about the complex needs of post-ICU patients may be a contributory factor to the negative stereotypes associated with this patient group. Ward staff are not trained to deal with the multifaceted problems faced by patients after ICU and providing relevant education would allow ward nurses to provide more effective care (Carr 2002).

Systems failures supplement and snack delivery

Other failings of the systems-based approach identified in this study were problems in the delivery of nutritional supplements and snacks. The current system in place in the hospital is fraught with pitfalls as there are numerous stages involved in the delivery of the nutritional supplements/snacks from the kitchen to the ward. The quote below illustrate this:

> ... they are not brought up, I forget about it, I forget to ask for them. (Patient 4)

> I'm meant to be taking one a day ... but it's a case of you know you've got to ask the nurses and of course they are so busy doing..... if they remember to, you know you've got to keep saying are you remembering so they're probably thinking what a pain. (Patient 5)

> I've no had them (snacks) since Sunday 'cause they said have you had your cheese and crackers and I goes I'm wanting scone and jam. They says right I'll go away and get you it and never came back and I've no had any snacks since then. (Patient 2)

This identified system failure resulted in reduced nutritional intakes in patients who were already nutritionally compromised. The researcher postulates that patients suffering from ICU-related delirium, a condition characterised by '*a fluctuating decline in attention, awareness and mental clarity, with disorganised thinking*' (Johns *et al.* 2010, p. 547), would struggle to remember to ask for supplements or snacks. Delirium is relatively common after a stay in ICU, although it is often under-reported and transfer to a new environment after discharge from ICU is a recognised causal factor (Johns *et al.* 2010). The researcher argues that this early ward period is when the physiological changes associated with critical illness are most prevalent, nutritional intake is at its lowest and there is the greatest need for supplements and snacks to aid calorie and protein intake.

Before discharge to home or community care

The NICE guideline states:

> give patients the following information before their discharge to home or community care. Also give the information to their family and/or carer, if the patient agrees
>
> If applicable, information about diet and any other continuing treatments. (NICE 2009, p. 13)

Pressure on acute care beds has meant that patients are discharged from hospital as early as possible. The findings from this study suggest that this drive for increased patient turnover places additional demands on discharge planning and has a detrimental effect on the provision of ongoing nutritional care.

In this study, the median length of ward stay was 10 days with over half of the patients being discharged home within a week of being transferred to the ward from ICU. Nutritional intake on discharge from hospital for the 10 patients who had a ward stay of less than a week was inadequate as none of the patients met their estimated nutritional requirements at the time of hospital discharge. Seven of the 17 patients in the study were not reviewed on the ward by a dietitian despite their nutritional care being handed over from the ICU dietitian at the time of transfer from ICU. Therefore, these patients would have received no nutritional intervention during their ward stay or nutritional advice on discharge from hospital nor any organised follow-up by community dietetic services.

Of the ten patients who were reviewed by a ward dietitian, six patients were discharged home with a supply of nutritional supplement drinks and advised to continue taking these at home. The three-month interview data suggested that patients were not following the recommendations from the hospital dietitian with some taking fewer nutritional supplement drinks than advised and others were not clear how many they should be consuming. The quotes below illustrate this:

> He's no been taking them (supplement drinks). (Patient 3 wife)

> We were doing two (supplement drinks) a day and we dropped off to one a day. (Patient 4 wife)

I take it (supplement drink) sometimes. (Patient 14)

All six patients who had been advised to continue taking nutritional supplements at home were referred to community dietetic services for follow-up. However, it was evident from the three-month post-ICU discharge interviews that none of these patients had seen a dietitian since discharge from hospital.

Four patients asked the researcher, whom they knew to be a clinical dietitian, for advice about their nutritional intake during the three-month post-ICU interview. The information requested included advice about foods that were high in protein, suggestions for high-calorie snacks, explanation about ongoing taste changes and ways to promote weight gain. The researcher also felt a professional responsibility to give therapeutic advice to a few of the patients who continued to struggle nutritionally.

It was apparent that current practice in the study setting does not correlate with the NICE (2009) guideline, which recommends that patients are given information about diet and any ongoing interventions. Patients did not receive appropriate nutritional advice on discharge from hospital as evident from the lack of clarity surrounding continuation of nutritional supplements and the numerous requests for additional nutritional information from the researcher at the three-month interviews. This suggests that the current service-based model of dietetic management, where patients are seen by different hospital dietitians depending on the area of speciality and separate community-based dietitians in primary care, does not facilitate continuity of care or allow the provision of timely nutritional advice and support.

Conclusion

Current practice does not reflect even the limited nutritional recommendations from the NICE (2009) guideline. This study has highlighted a number of organisational factors that influence the nutritional care of post-ICU patients, the effects of which are compounded by the complex range of problems experienced by patients after critical illness. Post-ICU patients are therefore at greater risk of malnutrition as a result of inadequate nutritional intakes. Further work needs to be undertaken to address ways to overcome these issues and develop a model of care that will improve current management of nutrition for patients recovering from critical illness.

Relevance to clinical practice

This study has relevance for all healthcare professionals who care for post-ICU patients. The findings indicate that organisational factors impact on nutritional care and further work needs to be carried out to address this.

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Contributions

Study design: JM, TW; data collection and analysis: JM and manuscript preparation: JM, PS.

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